

Middlesex University Research Repository

An open access repository of

Middlesex University research

<http://eprints.mdx.ac.uk>

Kock, Elizabeth (2016) The impact of a diagnosis of Asperger's syndrome on women's expectations of intimate relationships. Other thesis, Middlesex University and New School of Psychotherapy and Counselling. [Thesis]

Final accepted version (with author's formatting)

This version is available at: <https://eprints.mdx.ac.uk/19145/>

Copyright:

Middlesex University Research Repository makes the University's research available electronically.

Copyright and moral rights to this work are retained by the author and/or other copyright owners unless otherwise stated. The work is supplied on the understanding that any use for commercial gain is strictly forbidden. A copy may be downloaded for personal, non-commercial, research or study without prior permission and without charge.

Works, including theses and research projects, may not be reproduced in any format or medium, or extensive quotations taken from them, or their content changed in any way, without first obtaining permission in writing from the copyright holder(s). They may not be sold or exploited commercially in any format or medium without the prior written permission of the copyright holder(s).

Full bibliographic details must be given when referring to, or quoting from full items including the author's name, the title of the work, publication details where relevant (place, publisher, date), pagination, and for theses or dissertations the awarding institution, the degree type awarded, and the date of the award.

If you believe that any material held in the repository infringes copyright law, please contact the Repository Team at Middlesex University via the following email address:

eprints@mdx.ac.uk

The item will be removed from the repository while any claim is being investigated.

See also repository copyright: re-use policy: <http://eprints.mdx.ac.uk/policies.html#copy>

The Impact of a Diagnosis of Asperger's Syndrome on Women's Expectations of Intimate Relationships

Elizabeth Kock

January 2016, London, United Kingdom

Submitted to the New School of Psychotherapy and Counselling and Middlesex University Psychology Department in partial fulfilment of the requirements for the Doctorate by Professional Studies in Counselling Psychology and Psychotherapy.

Acknowledgements

First and foremost thank you to the women who participated in the study. You have enriched my understanding and awareness. I hope to transfer this to the clinical and research communities which cross my path throughout my career.

Thank you to my supervisors: Prof Digby Tantam for his valued comments and input. Dr Andre Strydom - there is so much to thank you for – facilitating the recruitment process, detailed and supportive feedback and reviewing my work countless times. Thank you to Dr Deirdre O’Brady who also supported the recruitment process and provided feedback on the analysis. Thank you to Dr Katrina Scior who provided input during the analysis.

Thank you to Fiona - for being there during endless marathon weekends, late nights and early mornings of reading, debating, arguing, disagreeing on and about this research. For generously sharing your thoughts on the subject with me regardless of the situation in which we found ourselves: be it whilst we took our walks, our swims or on our way to work. In this instance I would also like to thank Alexander, Linnet, Nonie and Christian for offering support in their own respective ways.

My mother has been a major source of support and encouragement throughout this process. Thank you for taking a keen interest in my work. And of course, thank you for the endless proof reading. Thank you to both my parents for opening the way to education.

Toubs, what is there to say... thank you. Thank you for all your support whilst completing this degree; for every ‘of course you can do it’; and ‘you work, I will make dinner/lunch/clean the house/run errands, etc.’; and ‘no, we don’t need to buy a house, I want to help you complete this degree’. Thank you for being interested in my work. Thank you for creating a space in which I could work effectively and for even buying me a cat so that physically, I never felt alone in this solitary process. Tot die laaste ster...

Dedication

Dedicated to the women who generously participated in this research.

Abstract

Women may present with slightly more subtle symptoms and could be more likely to only be diagnosed with Autism Spectrum Disorder (ASD) during adulthood, which may have implications for the way in which they view themselves, and for potential relationships. This dissertation explores the experience of intimate relationships of women who have been diagnosed with ASD in adulthood. Semi-structured interviews were used to interview eight participants. The data was transcribed and analysed using the Interpretative Phenomenological Analysis (IPA) method.

Four overall themes were identified: the first theme being 'Response to the diagnosis and receiving more information about ASD'. This theme has three sub- themes, i.e. emotional reaction to the diagnosis (which induced relief and loss); self-reflection since the diagnosis (e.g. feeling more coherent and less critical of themselves); and improved understanding of themselves. 'Factors influencing the decision to date' was another theme, consisting of three sub-themes which included reasons to date (e.g. experiencing a social pressure to date); reasons not to date (e.g. a preference to be on their own); and disclosing the diagnosis to partners/potential partners. The third theme related to 'Sex and sexual experiences'. This theme had three sub- themes, i.e. sexuality; difficulties relating to sex; and negative sexual experiences. The final theme was 'Experience of relationships as a person with ASD'. The three sub-themes that constitute this theme included: the challenges experienced in relationships (e.g. managing the spontaneous nature of relationships); positive aspects of relationships (which included companionship); and concerns regarding the future (which included worries about co-habiting and parenting).

The results of this study have implications for both research and clinical practice as it highlights the areas in which women newly diagnosed with ASD could benefit from support. These include adjusting to the diagnosis, disclosing the diagnosis to potential partners, and managing aspects of their intimate relationships. Further research in this area is required to be able to generalise and build on the results.

Statement of authorship

This dissertation is written by Elizabeth Kock and has research ethics approval from the New School of Psychotherapy and Counselling, the Psychology Department of Middlesex University and the National Health Service's National Research Ethics Service (UK). It is submitted in partial fulfilment of the requirements of the New School of Psychotherapy and Counselling and the Psychology Department of Middlesex University for the Degree of Doctorate of Existential Counselling Psychology and Psychotherapy. The author reports no conflicts of interest and is alone responsible for the content and writing of the dissertation.

Contents

ACKNOWLEDGEMENTS	1
DEDICATION	2
ABSTRACT	3
STATEMENT OF AUTHORSHIP	4
CHAPTER 1: OVERVIEW AND GENERAL DEFINITIONS	7
1.1 OVERVIEW	7
1.2 KEY DEFINITIONS	7
1.2.1 <i>Autism and Asperger's Syndrome</i>	7
1.2.2 <i>Intimate relationships</i>	8
1.2.3 <i>Date</i>	8
1.2.4 <i>Formal diagnosis</i>	8
1.3 KEY ACRONYMS	8
CHAPTER 2: LITERATURE OVERVIEW	9
2.1 INTRODUCTION	9
2.2 METHOD OF REVIEW	9
2.3 AUTISM SPECTRUM DISORDER (ASD)	10
2.4 THEORIES OF SOCIAL DEFICITS IN AUTISM	12
2.5 SECONDARY DIFFICULTIES AND CO-MORBID CONDITIONS	15
2.6 RESPONSE TO DIAGNOSIS	17
2.7 SOCIAL IMPLICATIONS OF HAVING ASD	21
2.8 ASD AND THE IMPACT ON INTIMATE RELATIONSHIPS	25
2.9 SEXUALITY AND SEXUAL BEHAVIOUR	26
2.10 CONCLUSION	30
CHAPTER 3: METHODOLOGY AND METHOD	31
3.1 AIM	31
3.2 SCIENTIFIC JUSTIFICATION FOR THE RESEARCH	31
3.3 METHODOLOGY	32
3.4 METHOD	33
3.4.1 <i>Phenomenology</i>	33
3.4.2 <i>Process of collecting data</i>	36
3.4.3 <i>Interviews</i>	39
3.4.4 <i>Process of the analysis</i>	40
3.5 ETHICAL CONSIDERATIONS	45
3.5.1 <i>Risk to participants</i>	45
3.5.2 <i>Risk to researcher</i>	46
CHAPTER 4: RESULTS	47
4.1 INTRODUCTION	47
4.2 RESPONSE TO RECEIVING THE DIAGNOSIS AND INFORMATION ABOUT ASD	50
4.2.1 <i>Emotional reaction to the diagnosis</i>	50
4.2.2 <i>"I'm not an alien..." - Self-reflection since the diagnosis</i>	54
4.2.3 <i>"I can't read your eyes because I have Autism" - Improved understanding of themselves</i>	56
4.3 FACTORS INFLUENCING THE DATING BEHAVIOUR	59
4.3.1 <i>"When are you getting married?" - Reasons for dating</i>	59
4.3.2 <i>"Better off with a book..." - Reasons for not dating</i>	62
4.3.3 <i>"Warts and all..." - Disclosing the diagnosis to potential partners</i>	65
4.4 SEX AND SEXUAL EXPERIENCES	71
4.4.1 <i>"...no such thing as a platonic relationship in this country ..." -Sexuality</i>	71
4.4.2 <i>"The map is a lot less clear..." - Difficulties relating to sex</i>	74
4.4.3 <i>"I felt like I was a cream cake he was looking at..." - Negative sexual experiences</i>	76
4.5 EXPERIENCE OF RELATIONSHIPS AS A PERSON WITH ASD	77

4.5.1	<i>“I like to see them as requests but people see them as rules...” – Challenges experienced in relationships.....</i>	78
4.5.2	<i>“I’m not very good at looking after someone else...” - Concerns regarding the future of relationships.....</i>	86
4.5.3	<i>“It’s what winning the lottery feels like...” - Positive aspects of relationships.....</i>	88
CHAPTER 5:	DISCUSSION.....	90
5.1	INTRODUCTION.....	90
5.2	STRENGTHS AND LIMITATIONS OF THE STUDY.....	90
5.3	DISCUSSION OF RESULTS.....	93
5.3.1	<i>Response to receiving the diagnosis and information about ASD.....</i>	93
5.3.2	<i>Factors influencing dating behavior.....</i>	95
5.3.3	<i>Sexuality and sexual experiences.....</i>	98
5.3.4	<i>Experience of relationships as a person with ASD.....</i>	99
5.4	RECOMMENDATIONS FOR FUTURE RESEARCH.....	101
5.5	IMPLICATIONS FOR CLINICAL PRACTICE.....	102
5.6	CONCLUSION.....	103
5.7	AUTHOR’S RESPONSE TO THE RESEARCH.....	103
5.7.1	<i>The Interviews.....</i>	104
5.7.2	<i>The Analysis.....</i>	104
5.7.3	<i>Revisiting the Data.....</i>	105
5.8	SUMMARY.....	106
APPENDICES	114
APPENDIX 1 – NHS ETHICS APPROVAL.....		114
APPENDIX 1 – MIDDLESEX ETHICS APPROVAL.....		115
APPENDIX 2 – PARTICIPANT INFORMATION.....		117
APPENDIX 3 – CONSENT FORM.....		122
APPENDIX 4 – INTERVIEW SCHEDULE.....		124
APPENDIX 5 – TRANSCRIBED INTERVIEW.....		127

CHAPTER 1: Overview and general definitions

1.1 Overview

The thesis is divided into four chapters. The first chapter is a *Literature Overview* providing an overview of the relevant background to the work, based on existing literature. This is followed by Chapter 2, *Methodology and Methods* which describes the methodological approach taken by the researcher, and consequently the method used to collect and analyse the data. The next chapter is Chapter 3, *Results* which depicts the results of the analysed data. Chapter 4 forms the *Discussion* and aims to contextualise the results within the academic literature. This chapter includes the author's personal reaction to the data and the subsequent analysis thereof. An overall summary of the research concludes the thesis.

1.2 Key definitions

1.2.1 Autism and Asperger's Syndrome

Autism Spectrum Disorder (ASD) is a developmental disorder which is characterised by persistent deficits in social communication and interaction. The disorder is also characterised by restricted, repetitive patterns of behaviour and/or interests. These deficits are present in early childhood and result in clinically significant functional impairment (APA, 2014).

It is noted that the research described in this thesis initially planned to focus on individuals with a diagnosis of Asperger's Syndrome. However, due to recent changes to one of the main diagnostic systems, The Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM-5), this diagnosis is no longer relevant and therefore the term Autism Spectrum Disorder (ASD) will be used throughout the thesis. Historically, Autism was sub-divided into four separate disorders: autistic disorder, Asperger's disorder, childhood disintegrative disorder, or pervasive developmental disorder not otherwise specified (APA, 1994). Current research (Huerta et al., 2012) suggests that most people who were diagnosed before the change in diagnostic criteria, will continue to meet the diagnostic criteria under the current classification system DSM-5 (2014).

The International Statistical Classification of Diseases and Related Health problems 10th Revision (ICD10) is the recognised diagnostic system in the UK. However, because the DSM-5 reflects the most recent changes to ASD diagnostic criteria and is the diagnostic system frequently used in research in the field of psychology, it is privileged in the current study.

1.2.2 Intimate relationships

An intimate relationship for the purpose of this study has been defined as one where a person has been on several dates with someone and resulted in sexual activity; or had the potential of becoming a sexual relationship.

1.2.3 Date

Two people getting together for an activity when the possibility of romance between them has been introduced but not dismissed.

1.2.4 Formal diagnosis

For the purpose of this thesis the term formal diagnosis refers to a diagnosis that a clinician has given an individual after a comprehensive clinical assessment. This excludes people who suspect that they have ASD but it has not been confirmed by a diagnostician. All participants in this study did have a formal diagnosis of ASD.

1.3 Key Acronyms

IPA:	Interpretative Phenomenological Analysis
ASD:	Autism Spectrum Disorder
AS:	Asperger's Syndrome
ADHD:	Attention Deficit and Hyperactivity Disorder
ToM:	Theory of Mind
DSM:	Diagnostic Statistic Manual

CHAPTER 2: Literature Overview

2.1 Introduction

This chapter will aim to provide a brief, selected overview of the literature considered relevant to the aim of the study. The literature reviewed in this overview will contextualise the current research study. The literature will briefly define Autism Spectrum Disorder (ASD) and the diagnostic criteria and then cover major theories of ASD. This will be followed by the social implications of the diagnosis and the experience of receiving a diagnosis of a developmental disorder in adulthood.

2.2 Method of review

The literature presented in this review was identified from a variety of sources; including focused key word searches on academic databases, academic books and their bibliographies.

The key words used in the searches included: Asperger's Syndrome, autism, intimate, sexual, romantic, relationships, sexuality, response, impact, experience to diagnosis, social experiences. These key words were used in various combinations with each other. The databases searched included EBSCO (PsychInfo and PsychArticles) and Medline (Pubmed). Middlesex University Library catalogue was also searched for academic books that were relevant to the current research study. Using the same key words, the Internet was searched using the search engine Google, including Google Scholar with the same key words. The aim of the general internet search was to access Internet blogs of people who have document their experiences of having ASD. The sites visited included Psychology today (<https://www.psychologytoday.com/>) and Autism-hub (<http://www.autism-hub.com/>). Any literature found was then hand searched for further relevant references. These searches were conducted throughout the process of this research study between 2010 and 2015, with no defined time boundaries.

This overview will summarise the sourced literature. The literature is discussed in more detail where it has particular relevance to the subject of the current thesis. For example, studies that shared methodological similarities with the current research and or had a similar aim.

2.3 Autism Spectrum Disorder (ASD)

ASD is a developmental disorder which is characterised by a number of symptoms as described by the DSM - 5 (APA, 2014):

- A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by: deficits in social-emotional reciprocity, deficits in non-verbal communicative behaviours used for social interaction, deficits in developing, maintaining, and understanding relationships.
- B. Restricted, repetitive patterns of behaviour, interests or activities, as manifested by at least two of the following:
 - 1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
 - 2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).
 - 3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g. strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).
 - 4. Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g. apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).
- C. Symptoms must be present in the early developmental period although it may not be obvious until social demands exceed limited capacities, or may be concealed by learned strategies in later life.
- D. The symptoms cause clinically significant impairment in social, occupational or other important areas of current functioning.
- E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Perhaps it is important to note that intellectual disability and autism spectrum disorder frequently co-occur; to make co-morbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

These deficits are present in early childhood and result in clinically significant functional impairment (APA, 2014). There is a discrepancy between the number of males and females diagnosed with Autism. ASD is estimated to be five times more common among males (1 in 2) than among females (1 in 189) (CDC, 2010).

The cause of the condition is to a large extent unknown. It is thought that ASDs are inheritable, however, the process of inheritance involves numerous genes (Persico & Bourgeron, 2006). It is also likely that genetic risk may be influenced by environmental factors. There are no proven treatments available to address the core symptoms of ASD. However, treatment can be offered to treat the secondary and co-morbid conditions that are often associated with ASD (Findling, 2005).

Historically an individual could be diagnosed with either 'Autism', 'Asperger's Syndrome' or 'Pervasive Developmental Disorder – Not Otherwise Specified'. More recently Autism and Asperger's Syndrome have been considered manifestations of the same disorder along a continuum (DSM-5; APA, 2014). There has been some disagreement in the literature regarding this re-classification. Historically Asperger's Syndrome was considered to be a different diagnosis, independent of Autism by virtue of individuals with Asperger's Syndrome tending not to display the cognitive and language deficits which (Asperger, 1944) considered to be characteristic of individuals with Autism (Kanner, 1943). Tonge, et al., (1999) provided more recent support for Kanner's views. They identified individuals with Asperger's Syndrome as exhibiting greater psychopathology than individuals with High Functioning Autism. Furthermore, they found that individuals with Asperger's Syndrome exhibited higher levels of anxiety and greater social impairment than individuals with High Functioning Autism, whilst controlling for differences in age and cognitive ability. They therefore concluded that Asperger's Syndrome and High Functioning Autism were distinguishable disorders. In his review paper, similar to the position taken by the latest version of the Diagnostic and Statistical Manual, the DSM-5, Sanders (2009) concluded that the difference between High Functioning Autism and Asperger's Syndrome might be 'different qualitative manifestations of the same disorder' (p 1566). This supports the initial position of Hans Asperger, that both Autism and Asperger's Syndrome were present along the same continuum of difficulties.

According to Asperger (1944) some cases of ASD are not diagnosed until later in life. The difficulties that individuals with ASD have are particularly noticeable in transitional periods, such as changing or

leaving school or seeking employment, due to difficulties with adapting to new circumstances or environments (Tantam, 2000). This may provide an explanation for difficulties not being detected and diagnosed until adulthood. This is problematic when considering research, which suggests that early behavioural intervention can be effective in ameliorating some of the difficulties associated with having ASD. Howlin et al., (2009), reviewed the research on controlled studies of early behavioural interventions for individuals with ASD. They concluded that there is some evidence that early intervention could ameliorate some difficulties associated with ASD. However, individuals diagnosed with ASD during adulthood are unlikely to have benefited from such advances when they were children.

2.4 Theories of Social Deficits in Autism

Although there is not a single, widely accepted explanatory cognitive theory of ASD, several theories have been posited in the literature, which attempt to explain the central, social and communication deficits that are characteristic of the disorder. Some of the prominent theories will be described in brief below. For further discussion of the theories of ASD see Levy (2007) and Tantam (2009). Baron-Cohen et al., (1985) first proposed that people with ASD have difficulty inferring the mental states of others. They termed the ability to infer the mental states of others as Theory of Mind (ToM) and suggested that deficits in ToM lead to an inability to attribute beliefs to others; individuals with ASD are thus at a grave disadvantage when having to predict the behaviour and demeanour of other people (p 43). Proponents of the existence of ToM deficits in individuals with ASD suggest that a deficit in ToM may cause difficulties in negotiating the complexity of relationships. Thus in the context of managing and negotiating relationships, in particular intimate relationships, a ToM impairment may fundamentally affect the nature and maintenance of complex relationships .

Supporting the ToM theory, is the research by Crichley et al., (2000) and Schultz et al., (2000). These authors set out to investigate if people with ASD were more or less likely to accurately judge the facial cues and facial expressions of others. They posited that deficits in ToM would prevent an individual from being able to identify the emotional states of others based on visual cues, when these were different to their own experience. Both studies concluded that participants with ASD scored significantly lower on judging facial cues accurately than a non-ASD control group. The authors of these studies suggested that their research had demonstrated impaired ToM in

individuals with ASD. Conversely, other research has demonstrated that individuals with ASD are capable of passing some tests designed to measure ToM but that they experience delays in acquiring the ability to infer the intentions behind the actions of others. They are more prone to make errors on advanced ToM tests which include Reading the Mind in the Eyes Test (Baron-Cohen et al., 2001) and The Voice Test (Rutherford et al., 2002).

Castelli et al., (2002) suggested that ToM could otherwise be referred to as a capacity for mentalisation. Baron-Cohen et al., (1985) predicted that having the ability to mentalise another's position is fundamental to normal development of social, communicative and imaginative skills, and that abnormalities in this area are a core feature of individuals with ASD. On the other hand, deficits in mentalising capacity are not exclusive to individuals with ASD. Poor mentalising capacity has been demonstrated in other clinical populations, including those diagnosed with schizophrenia (Corcoran, 1997), anorexia (Russel et al., 2009), and Personality Disorder, (Bateman and Fonagy, 2009) in accordance with a medical model of mental illness. The capacity to mentalise is thought to be a product of 'good enough' early childhood experiences and individuals who have experienced trauma and a lack of responsive caregiving in childhood may not fully develop this capacity (Fonagy et al., 2014). Thus, these individuals may fail tests designed to measure ToM in a similar way to individuals with ASD. Therefore, deficits in ToM or the capacity to mentalise in themselves are not necessarily an indication of ASD. It also highlights the need for sound methodology and testing to enable differentiation between those with ASD and those whose difficulties can be attributed to another psychological disorder.

As mentioned above, whilst mentalisation deficits in individuals may be associated with ASD, the theory, in itself, is not sufficient to explain many of the other characteristics of individuals with ASD. These can include having a restricted range of interests, an obsessive desire for sameness, a preference for concrete rules, relative strengths in certain cognitive tasks, savant abilities and pre-occupation with parts of an object (Frith & Happe, 1994).

Another theory of ASD was provided by Frith (1989) who proposed the theory of Central Coherence. She defined Central Coherence as an ability to draw diverse information sources together, considering their context and consequently, construct a higher level meaning of the integrated information. On this basis, Frith (1989) proposed that individuals with ASD have deficits in this ability resulting in their inability to integrate information at different levels. Central Coherence Theory provides an explanation for some of the characteristics of ASD not explained by ToM deficits. For

example, the pre-occupation with parts of an object can be attributed to difficulties with processing each component part and putting them together to create a meaningful whole.

It is noted that deficits in Central Coherence can also be present in other disorders. For example, there is research suggesting that individuals with a diagnosis of psychosis (Yeragani et al., 2006), anorexia nervosa (Lopez et al., 2008) and individuals who have experienced trauma (Cook et al., 2009) may focus on specific elements of situations and appear to ignore or not integrate the broader context into their processing of the situation. These struggles are reminiscent of those of individuals with ASD who may have difficulty in integrating information in the same way.

A third theory relates to sensory sensitivity. In her review of the research on sensory sensitivity, Bogdashina (2013) explained the premise for the Sensory Theory of Autism. In essence, individuals with ASD have more sensory sensitivity than the general population. This sensitivity causes anxiety, and may result in the development of behavioural adaptations and coping strategies in order to accommodate these sensitivities. This, in turn, may manifest as difficulties which are traditionally deemed to be the core symptoms of ASD: difficulty in social communication and compulsive behaviours. However, a critique of this theory could be that while other clinical population groups may also experience sensory sensitivity, it does not manifest in the same way as in people who have ASD. Therefore, the sensory sensitivity itself and the way sensory input is managed and processed should be considered together.

Sensory Processing refers to the way in which sensory information is processed and managed by individuals. If it is managed in an expected way, individuals are able to give responses that are consistent with environmental expectations. This enables individuals to engage functionally in society (Johnson-Ecker & Parham, 2000). However, for this to happen, both efficient reception and integration of incoming sensory information are necessary (Bundy et al., 2002). If the information is received and/or managed in different ways to what is expected, it could lead to difficulty in engaging in everyday life. This theory has some empirical evidence. Baker et al. (2008) set out to investigate sensory processing patterns in children with ASD. The authors asked the children's caregivers to complete a questionnaire relating to the children's sensory integration patterns. The results showed that their sample (children with ASD) had a specific sensory processing pattern and that this pattern correlated with social, emotional and behavioural functioning. Robertson and Simmons (2015) set out to investigate the sensory experience of adults with ASD. The authors captured their data by holding a focus group with six adults with ASD (one woman and five men). They analysed the data

through general inductive qualitative approach (Thomas, 2006). Their findings suggest that adults with ASD may also experience sensory sensitivities.

In contrast to the above theories, Tantam (2009) suggested that ASD deficits are symptoms of a more general difficulty in understanding non-verbal communication. Further, Tantam highlighted that non-verbal communication can be subliminal as well as in the form of overtly visible social cues. Tantam referred this as the 'Interbrain Theory' of Autism. Tantam proposed that neuro-typical individuals can be described as computers that are linked together and constantly being updated by the social world around them and their experiences/interactions. He argued that the brains of people with ASD are not linked together in the same way, so that these individuals are not able to receive similar 'updates' from their experiences or interactions. That is, in individuals with ASD, brain function may be described as more autonomous and without the benefit of additional information processing and memory provided by 'updates' from other brains; i.e. referring to the input we receive from other people through engaging in social interactions. The 'Interbrain Theory' allows for a useful clinical understanding of individuals with ASD, who tend to interact with others on the basis of concrete rules, and are likely to require support to constantly generate new rules or procedures as they progress through different contexts of the life-span. For example, if an individual with ASD has a procedural rule or understanding which helps them to effectively interact socially in a lecture theatre, they are likely to also need access to a different rule if the context changes to an after-lecture drink in the pub. The 'Interbrain Theory' may also allow for the obsessive desire for sameness often seen in individuals with ASD. If individuals are not able to readily update their understanding of the social world, they may be more driven to try and shape their world to remain predictable. It is noted that whilst this theory may have some face and anecdotal validity, there has been limited research focusing on validating it.

Although all the above mentioned theories do not individually provide an encompassing explanation for ASD, they help to increase understanding of the ASD related difficulties and may lead to focused interventions.

2.5 Secondary Difficulties and Co-morbid Conditions

There is growing evidence to suggest that individuals with a diagnosis of ASD can often present with co-morbid mental or emotional health conditions (Tantam, 2000; Howlin & Moore, 1997; Hofvader et al., 2009; Ghaziuddin et al., 2002; Tantam, 1988). Affective disorders are amongst the most

prevalent co-morbid conditions of ASD. Hofvader et al., (2009) investigated the prevalence of co-morbid conditions in adults with ASD. Their findings indicate that mood disorders were most frequently experienced by participants followed by anxiety disorders.

Research in this field could easily be confounded by the presence of co-morbid difficulties in individuals with ASD, which will to some extent prevent ASD from being explored as a separate concept.

Tantam (2000, p 56) summarised the possible reasons for the prevalence of affective disorders in individuals with ASD as follows:

- Family tension or broken family ties
- A higher than usual rate of adverse life events
- Victimisation as a result of not being able to read social situations or being different
- The awareness of being different
- Rumination over past injustices, resulting in aggression
- Relationship breakdown

There may, therefore, be a psycho-social element to the production of difficulties experienced by individuals with ASD. That is, some of their difficulties may be caused by social responses and the stressors a person with ASD may experience.

Individuals with the diagnosis of ASD may be able to maintain a career and/or relationship, however, this apparently high level of functioning could conceal an internal struggle as a consequence of the effort required to present themselves in a certain way. If problems are not identified and individuals are not provided with the necessary support at an early stage it may compound existing difficulties, which may lead to emotional and psychiatric problems.

Various researchers have posited that an awareness of being different may cause distress in individuals with ASD and result in negative implications on how they view themselves (Muller et al., 2008; Punshon et al., 2009). Van Deurzen (2010) noted the double effect of relating i.e. whatever is related to, relates back and therefore a sense of self is formed. Hobson (2010) too noted 'in a social world it matters what people (including myself) think and feel about me, as well as what I think and feel about others' (p 392). Furthermore, Hogg et al., (1995) emphasised the importance of interaction by stating ... 'self is a product of social interaction, in that people come to know who they are through their interactions with others; in this perspective, a core mechanism is that of

‘taking the role of the other’ (p. 258). Therefore, it is possible to understand why individuals who struggle to process and interact in a social context may consequently develop difficulties relating to how they view themselves.

The struggle to process and interact within a social context might in itself cause a person to isolate themselves (Punshon et al., 2009). This is likely to be a common experience for individuals with ASD. Research demonstrates that social isolation can be a risk factor for affective disorders (Coie et al., 2000).

In summary, individuals with ASD experience a variety of co-morbid mental health conditions. Some of the hypothesised causes of these are related to their interactions within the social world. It is, therefore, challenging to separate the aetiology of ASD from that of the co-morbid conditions.

2.6 Response to Diagnosis

The response to receiving a diagnosis could be dependent on not only the nature of the diagnosis, but also what the diagnosis could mean or represent to the diagnosed person. There are differences in the response to receiving a diagnosis of a physiological illness compared to a neuro-developmental disorder. In the case of a neuro-developmental disorder, symptoms have been present since childhood and in the case of ASD there is no cure. ASD is not thought to be a progressive disorder, therefore, it is not possible to estimate how the difficulties might affect an individual over time. This section provides a brief overview of the literature found on responses to a diagnosis of a neuro-developmental disorder. Given the limited literature on responses to an ASD diagnosis in adulthood, the literature on other neuro-developmental disorders will also be explored.

Punshon et al.’s (2009) research had a similar goal and methodology to the current study. The authors set out to investigate the experience of receiving the diagnosis of Asperger’s Syndrome in adulthood and aimed to explore if participants’ experiences could be explained by cognitive or staged models of stress and how services could support an individual who has received this kind of diagnosis. Punshon et al., (2009) applied a phenomenological approach in examining the experience of ten adults (seven males and three females) who had received a diagnosis of ASD. The results of the analysis using IPA suggested six overall themes. These included:

- Negative life experiences: participants reported their negative experiences before the diagnosis, especially in childhood. These experiences included feeling that they were not accepted by peers and feeling that they did not belong. These experiences were particularly traumatic. Participants also reported that they were often victimised. In these instances some of the participants responded by isolating themselves and limiting their social interactions.
- Pre-diagnostic experiences of services: this theme captured the participants' experience of mental health services prior to receiving a diagnosis of ASD. All except one participant had engaged with mental health services throughout their life. Participants also reported on the experience of being misdiagnosed. This resulted in treatment not being successful and consequently re-enforcing their beliefs that they were different to others. Some of the participants who reported on the experience of being misdiagnosed also reported that this had implications on how they currently viewed services and the amount of faith they had in the validity of their current diagnosis. It is perhaps worth noting that although all of the participants received a formal diagnosis in adulthood, a diagnosis of ASD had been suggested to some participants during childhood. However, these suggestions were not pursued. In these instances, participants believed that this was because their families were in 'denial' about the possibility of them having these kinds of difficulties and in addition, were apprehensive due to the stigma attached to ASD at the time.
- Beliefs about symptoms of ASD: this theme captured the experience of participants who believed they did not fit in with their peer groups. Participants were mostly aware that they were different to their peers. Consequently, this led to attempting to mask their difficulties, although they believed that these attempts were unsuccessful.
- Identity formation: due to having no explanation for their difficulties and receiving the diagnosis only later in life, participants reported experiences of being susceptible to criticism and being victimised. Seven participants reported that they had internalised criticism they received from others. Seven participants also believed that not having a rationale for their difficulties gave way to them experiencing additional mental health difficulties, such as affective disorders and self-harming behaviours.
- Effects of diagnosis on beliefs: participants reported a range of positive and negative consequences to receiving the diagnosis. Participants reported that the diagnosis provided a context which allowed them to explain their difficulties to others; and reported that because the diagnosis provided an acceptable rationale for their difficulties, they no longer experienced being blamed for this. One participant described this experience as being

'exonerated' (p 277) of blame from previous difficulties. They also reported experiencing relief, as well as feeling anger and loss. Some participants reported that they experienced frustration when considering that their difficulties were likely to be lifelong. Participants also reported that they felt more connected to others who share similar difficulties, which brought about a sense of belonging.

- Effects of societal views of ASD: some participants reported that their families were not surprised by the diagnosis. Some participants reported that their families also experienced relief when they were told about the participant receiving the formal diagnosis. Participants ascribed this to the fact that their family members no longer felt responsible for the participants' difficulties. Some reported negative reactions from family members. This was ascribed to the family members having their own difficulties which made it hard for them to grasp or understand the diagnosis. In all of the responses which the participants received from the people around them, a lack of understanding of the disorder's associated difficulties was evident. Participants' perceptions of the diagnosis were also influenced by the portrayal of Autism by the media.

The sample in the study described above was not homogenous: The study included both genders of which a third were female, and individuals at different time periods since diagnosis and possibly different stages of stress. All of these factors may limit the extent to which the findings could be applied to a specific group of individuals.

A second criticism of Punshon's (2009) study is that there is no definition as to how the data was interpreted. The themes were thoroughly verified through multiple rounds of different groups (peer and participant) reviewing the analysis. However, the article provided no description of the researcher's own epistemological position, which informed the original interpretation of the data. Being transparent about the epistemology that underpins the interpretation is crucial in any IPA study (Yardley, 2000).

Attention Deficit Hyperactivity Disorder (ADHD) can be compared to ASD with the important difference that in the case of ADHD, there is medication available for symptom management. However, there are also several similarities: it is also a condition present in childhood, which may continue into adulthood, and a person with ADHD may also experience negative feedback from others due to the nature of their behaviour.

A qualitative study by Young et al., (2008) captured the experience of eight people (four men and four women) who received the diagnosis of ADHD in adulthood. This study was similar to the current study as it aimed to capture the experience of an adult diagnosis of a neuro-developmental disorder. The participants interviewed by Young et al. varied in age between 21 and 50 years. The length of time between diagnosis and research interview ranged between 7 months and 6 years. The data was captured through semi-structured interviews and analysed through an Interpretative Phenomenological Approach (IPA). The researchers derived three themes from the analysis:

1. Review of the past: this theme captured some of the negative past experiences of the participants. These experiences included feeling different to others (including peers and family) and being particularly prone to criticism from others. This usually presented in the form of having been given emotionally-laden labels such as 'lazy', 'disruptive' and 'stupid'. Participants responded to this kind of feedback by either accepting the label as fact or they simply ignored or dismissed these kind of statements. The participants who had children at the time of the interview recognised how their own children could possibly be experiencing similar difficulties to those the participants themselves had experienced as children.
2. Emotional impact of diagnosis: this theme represented the emotional responses of participants and the subsequent process of adjustment after having received the ADHD diagnosis. The authors report that the adjustment process included relief and elation since receiving the diagnosis, as they now had rationale for their difficulties after many years of searching for reasons to explain their difficulties. The rationale was helpful as it supported an understanding that they were not responsible for their difficulties. The relief was followed by confusion and emotional turmoil. After this, anger at receiving the diagnosis later in life set in because of having to endure an 'unnecessary struggle' (p 497) earlier in their lives, due to not having the understanding or rationale for their difficulties. The anger also translated to sadness and grief as they became aware that they had for some time believed that their difficulties were inevitable. The sadness was followed by anxiety as participants came to realise that their difficulties were lifelong. The final stage of adjustment included accepting the diagnosis.
3. Future considerations: this theme represented the participants' reports of an awareness of a stigma that is attached to ADHD. This awareness brought about consideration of issues such as how to disclose the diagnosis to others. Another aspect of this theme included feelings of achievement and hope. This was largely attributed to the medication taken as it brought improved functioning in everyday tasks. However, when the effect of medication wore off

participants reported that they re-experienced symptoms and some of the emotional reactions previously mentioned.

The study outlined above offered insight into the variety of emotional responses a person receiving the diagnosis of a neuro-developmental disorder could experience. The time differences which lapsed between receiving the diagnosis and the interview, is noted and could have resulted in some participants having had time to adjust to their diagnosis to a greater extent. The researchers did not offer insight into factors that could have confounded the participants' reported experiences. Such confounding factors could include access to emotional support services which may have provided participants with the opportunity to actively rethink their experiences, differences in participants' understanding of ADHD, and differences have in participants' ages.

In summary, both these studies found that participants experienced negative past experiences associated with having a neuro-developmental disorder which they attributed to not having a rationale to explain their difficulties. In addition to this, receiving the diagnosis led to a complex emotional process. Both studies also referred to a dilemma participants experienced regarding disclosure of the diagnosis. The complexity of these difficulties point to the need for support for the diagnosed person. This could include providing the diagnosed person with post diagnostic counselling to support the process of making sense of the diagnosis. It could also be helpful to support the family and social circle of the diagnosed person to understand the difficulties the person faced and to understand that some of the diagnosed person's behaviour should be interpreted within the context of having the difficulties that are clinically significant. On a more macro level, it could also be a helpful intervention to address stigma. This intervention could perhaps address the stereotypes about people with ASD and other developmental disorders held by the general population.

2.7 Social implications of having ASD

An intimate relationship is primarily a social relationship and therefore the social implications of having ASD is relevant to the current study. The difficulties people with ASD have in interacting within the social environment are well documented throughout the literature (Tantam, 2000; Howard, Cohen & Osborne, 2006; Muller et al., 2008). In giving a personal account of living with ASD, McKean (1998) compared his own personal experience of having ASD in the social environment

to 'a space probe on an alien landscape' - suggesting that the world around him appeared unfamiliar and consequently he felt feeling out of place and alone. In another personal account, Lawson (2001) emphasised that her desire for social relationships remained despite lacking the knowledge and subtle skills that are required for building friendships. Although personal accounts hold value as a first-hand account of the experiences of a person with ASD, it is not always known if the person providing the self-report actually had a formal diagnosis of ASD. Therefore, caution is advised when interpreting such statements.

Soraya (2012) provided a further account of difficulty in understanding social context:

"There are times when I find the social world of others mystifying. Within my understanding of the social world, I try to reach out to others, care about others, and be the best person that I can be, but there are times that I feel that I am spinning my wheels. My overtures to express love fall into the abyss of Asperger's - creating wide distances between me and those I love.

It can make me very angry - angry at the misunderstandings, frustrated at the judgments imposed upon me by those misunderstandings, and aggravated at the persistence of those misunderstandings, despite my repeated attempts to make myself understood. Do we all have to be the same to be accepted in this world? Is the simple fact of having Autism or Asperger's mean a lifetime of aloneness, even when you are with others?"

Scheeren et al., (2010) referred to an analogy used by Levine & Feldman (1997) comparing an individual in the social environment to an actor; an actor can manipulate the audience's impression by directing his/her performance. This is achieved by taking into consideration the expectation of the audience, being aware of one's own capacity to react to the response and the ability to link the expectation to this in order to create the required impression. In individuals with ASD this kind of self-presentation is not as spontaneous and might need more active or intentional social awareness compared to neuro-typical individuals. In turn this could have affected their ability to spontaneously behave in a socially acceptable fashion and therefore could adversely impact on their social relationships due to the effort it requires to sustain these relationships.

Muller et al., (2008) investigated the social experiences of eighteen individuals (twelve men and six women) with ASD using semi-structured interviews. The analysis of the interviews identified six themes which reflected participants' reported experience of their social worlds. The themes are stated and summarised below:

1. Intense isolation: participants described being isolated both as children and later on in adulthood. As they grew older, the impact of this became more severe as did their awareness of being different.
2. Initiating/lack of lasting friendships: this theme related to not being able to establish and maintain lasting friendships and being isolated; causing depression and anxiety.
3. Communication difficulties: participants reported that communication difficulties inevitably had an impact on socialising. Specifically they struggled to follow or interpret non-verbal communication (e.g. tone of voice and gestures) in social settings.
4. Longing for intimacy: participants voiced the desire to have and maintain more intimate relationships. In this regard participants also disclosed that although they had a desire for intimacy, they feared not knowing what it might entail.
5. Need for contributing to the world around them: In this instance participants reported a need to volunteer and be part of society.
6. Effort to develop social/self-awareness: participants reported that they made efforts to develop an awareness of themselves and the social world. They did this by participating in support groups and furthering their own knowledge regarding the disorder by reading about it.

These themes indicated that individuals with ASD experienced a need to be social on many different levels of the social system in which the individuals live and interact. However, participants felt isolated and lacking in social and intimate relationships despite their social and communication limitations.

The findings of the above mentioned study should be considered in the context that the interviews were conducted by different interviewers. Therefore, the specific interpersonal qualities of each interviewer may have led to some variation in what participants were willing to speak about with the interviewer. There was also a high level of variance in the sample in terms of age at the time of diagnosis, and the amount of time between diagnosis and participation in the study. These factors may have led to biases in the resultant data. For example, participants who had their diagnosis longer may have had more time to understand and adapt to their difficulties. Finally, not all participants taking part in the Muller et al., (2008) study, had a formal diagnosis of ASD at the time of the interview. Consequently, it is difficult to confidently conclude that the difficulties and experiences reported during the interviews could be directly attributed to having ASD.

Despite some of the limitations of the study, it highlights the desire for relationships in a person with ASD and challenges traditionally held beliefs around the disorder, in particular that these individuals may socially distance themselves from others intentionally (Muller et al., 2008). This is in line with findings of the study by Punshon et al., (2009) which also highlighted the need for friendship, despite the social difficulties faced by people with ASD.

Sperry & Mesibov (2005) explored the dilemma between the need for social relationships while having limited skills to access this, and asked eighteen participants (of whom only one was a woman) to each provide a single question which they had about how to 'get along with' other people (p 367). The researcher read each anonymised question to the group. The group then discussed possible solutions to the questions they had generated.

The researchers conducted a content analysis with two researchers independently analysing data. The questions that the participants generated were grouped into four themes. These themes were:

1. Developing and maintaining interpersonal relationships
2. Behaving appropriately around members of the opposite sex
3. Maintaining relationships at work
4. Personal perspectives on being diagnosed with ASD. This theme related to questions about how participants experienced their diagnosis as 'being an obstacle that challenged their social interactions' (p 372).

Overall these themes demonstrated the specific social challenges participants experienced in everyday situations and the need for social interactions.

The results of this study should be interpreted within the context that all of the participants were recruited from an established social group. This in itself may be indicative that the participants wanted to engage in social interactions and may therefore limit the generalisability of the results. Additionally, the interviews were completed within a group context. It is therefore possible that group dynamics could have influenced the nature of questions asked and solutions offered.

2.8 ASD and the impact on intimate relationships

Erikson (1968), in his theory of development, described how the types of relationships we strive to achieve change over time. He posited that as the individual moved into early adulthood the focus shifted toward the establishment of intimate relationships. This indicates that intimate relationships may be an important area of research when considering adults with ASD, particularly given their identified difficulties in functioning within other relational contexts. An important consideration when exploring this area in individuals with ASD, is likely to be that of gender. Males and females are subject to specific societal expectations and stereotypes (Auster & Ohm, 2000).

There appears to be very little research literature in which the experience, nature and quality of intimate relationships for individuals with ASD is explored. Despite this, it is hypothesised that the specific symptoms of ASD may make it difficult for an individual to establish and maintain this type of relationship. The difficulties surrounding social and emotional understanding are likely to have a particularly strong influence when it comes to intimate relationships. For example, Simone (2010) stated that women with ASD are often not aware of the social expectations partners have for each other when engaged in a relationship as these are specific and often not generalisable; based on the ability or inability to read the other person's experience rather than on objective rules.

There may be other factors in addition to the primary difficulties associated with ASD that also have an influence on how people with ASD engage in, and experience relationships. One of these factors could be that a person with ASD may lack in the ability to respond to the emotional needs of a partner when they are not explicitly expressed. This in itself could lead to relational difficulties. People with ASD may try to compensate for this by imitating what they witness through observation of other individuals and media portrayals of relationships. This could cloud their notion of intimate relationships and what it entails and may also impact on the quality of the relationships. It could be that people without ASD also do this, i.e. draw on observing others and media portrayals to inform their notion of intimate relationships. They however, unlike people with ASD, are likely to have the option of calling on other abilities to structure, interpret and engage in relationships. Blackshaw et al., (2001) suggested that people with ASD may rely on a large set of inflexible, learned social rules and required a high level of self-consciousness in order to monitor the use of these rules in social interaction. Rules about potential interactions may not be effective when managing a relationship such as an intimate relationship because of the emotional nature of such relationships. This could

lead to further complications and friction in how relationships are managed. 2.9 Sexuality and sexual behaviour

Sexuality plays an important role in the physical and psychological health of a human being (Swango-Wilson, 2008). Research indicates that, despite their difficulties with interacting in the social world, some people with ASD are interested in establishing sexual relationships (Henault, 2005; Tarnai & Wolfe, 2008) and therefore will have some bearing on the current research.

There has been limited research directly exploring sexuality in individuals with ASD. The studies that have been found will be described in some detail below. Byers et al., (2013) studied the sexual functioning of single adults with high functioning autism. The study included both men and women and had two primary goals; to determine whether single individuals with HFA with more autistic symptoms were less likely to have relationship experience, and to describe the sexual functioning of single individuals with HFA. The second goal relates more to the current study and will therefore be focused on. It is noted that the participants in the study described were recruited online. This means that the authors were not able to confirm the diagnosis of ASD. It is also noted that participation in the study was voluntary, therefore, it may be that the sample was biased in that those with an existing interest in sexuality may have been more likely to volunteer to participate. They did try to control this by asking participants to complete an ASD screening measure. Although all the participants were single at the time of participating in the study, 59% of them did have past experience of relationships. It is noted that the study did not describe their definition of relationship, which may have led to some lack of clear reference point for participants when responding to the study questions.

The demographic information provided on participants in the study by Byers et al. (2013) highlighted the distribution of different sexual orientations amongst the group of individuals with ASD. When asked about their sexual orientation, 58% identified themselves as heterosexual, 15% as homosexual, 9% as bisexual, 12% as unlabelled and 5% as unsure.

Participants in the Byers et al.'s study referred to above, were asked to complete a number of sexuality related questionnaires, which were designed to measure a number of areas; including sexual knowledge, sexual arousability, sexual anxiety, sexual desire, level of sexual activity, general sexual functioning, sexual experience, online sexual behaviour and sexual problems. Overall, the

study found that the participants with HFA had good sexual functioning, good solitary sexual functioning, reported a moderate desire for solitary sexual activities and had a good level of sexual knowledge. Participants reported a moderate desire for dyadic sexual activity and moderate sexual arousability. Most of the participants had not engaged in any sexual activity within the previous month. The authors argued that there was an overall indication of good sexual functioning in their sample. They suggested therefore, that sexual frequency is dependent on ability to access suitable partners, which may be hindered by ASD related social communication skills deficits and individual motivation to find a partner. It could also be that the discrepancy between sexual functioning and sexual experience is a result of factors not measured by the authors of the study; participants may be exposed to wider societal views and socio-cultural factors that are not necessarily related to sex. For example, individuals with ASD are likely to be exposed to religious or family values that influence their engagement with sex and beliefs about sexuality.

Byers et al.'s (2013) study did find that participants who reported having never experienced relationships showed poorer sexual functioning in several areas; including, lower sexual arousability and fewer positive sexual thoughts. The authors argued that the absence of sexual relationship experience for some participants could be due to not having an interest in sexual relationships. They hypothesised that this might be because of the identified difficulties in sexual functioning. However, participants with and without relationship experience did not differ in their desire for, or frequency of solitary sexual activity; indicating that it was not that they were less sexual but that they were less inclined to engage in sexual activity that involved another. It is not clear whether these results would be comparable to neuro-typical individuals or whether they are specific to individuals with ASD. The study also found a number of gender differences between the participants. The men in the study reported better sexual function than did the women in a number of areas. However, the men and women did not differ on their sexual knowledge. Perhaps most applicable to the current study, women reported higher sexual anxiety, lower sexual arousability, lower desire for solitary and dyadic sexual activity, less frequent solitary sexual activity and fewer positive sexual thoughts and more sexual problems.

In another study, Byers & Nichols (2014) aimed to explore the sexual satisfaction in adults with high functioning autism who were in relationships. They found a high level of variance in relationship duration with the longest relationship being 40 years. It is noted that only 40% of participants had a formal diagnosis of ASD. It is therefore not clear on what basis the other 60% of participants were thought to have ASD. The authors attempted to understand sexual satisfaction within the population

group by measuring sexual satisfaction, global relationship satisfaction and perceived sexual rewards and sexual costs. The authors found that ASD symptoms adversely affected adults' experiences in their sexual relationships through reducing sexual rewards and relationship satisfaction and increasing sexual cost.

Perhaps also interesting is that Byers & Nichols (2014) found no differences between men and women in their sexual satisfaction or in any of the variables they measured; this may suggest that women and men with ASD experience their sexual relationships similarly. However, the men did report lower relationship satisfaction than women. The authors hypothesised that this was because women might have more of a realistic expectation of relationships than men due to them being exposed to more information about relationships and having peer groups with whom they discuss relationship issues. It is noted that they did not specifically measure these factors, thus limiting the applicability of the conclusions they have drawn. Additionally, the authors did not provide information relating to the specific mediating factors between gender and relationship satisfaction. More research is required in order to support the understanding as to whether the relationship experiences and sexuality related factors in individuals with ASD, are different to those of the neuro-typical population. Gilmore et al., (2011) aimed to explore this area when they compared the sexual attitudes and behaviours of people with ASD with those of neuro-typical individuals. Again this research was completed online; meaning that there may be limitations in terms of establishing the validity of the sample groupings and in terms of the type of people likely to respond to surveys of this nature.

Gilmore et al., (2011) found that people with ASD did show an interest in sex and engaged in sexual behaviours with no significant differences between the ASD group and non-ASD group on the variables they explored. They also found no differences between the ASD participants and the neuro-typical participants in terms of their comprehension of sexual language. The only difference they reported was a higher prevalence of individuals identifying themselves as being asexual in the ASD group.

It is noted that much of the research in this field is constrained to defining relationships in terms of men and women. This may be problematic, particularly given that Gender Identity Disorder (GID) appears to be more prevalent within the ASD population than in the neuro-typical population (Robinow & Kudson, 2005). The GID prevalence rate in women generally ranges from 1:30 000 to 1:50 000 (Zucker & Lawrence, 2009). The prevalence is higher in ASD population groups and is

estimated to be 60:10 000 (men and women included) (Fombonne, 2005). Questions on gender identity are not raised in many of the studies exploring sexuality in individuals with ASD.

As mentioned above, people with ASD do desire social and sexual relationships. It is hypothesised by the current author that their deficits in social communication skills may hinder some of them from establishing and maintaining this type of relationship.

Engaging in intimate relationships could result in a person with ASD being vulnerable to maltreatment. It could be hypothesised that because of their social naivety, individuals with ASD might be more vulnerable to abuse and manipulation in relationships. Simone (2010) suggests a person with ASD will not necessarily realise if they are being maltreated perhaps due to doubting their own ability to understand complex relational situations. This is supported in the wider literature on abuse and maltreatment which indicate that population groups with a neuro-developmental difficulties are more prone to sexual abuse (Martin et al., 2006).

Another area that may be important to consider when thinking about sex and individuals with ASD, is the sensory nature of sexual activity. A characteristic of ASD can include difficulties with sensory processing, including touch (APA, 2014). There is limited research available on the sensory issues relating specifically to sex and people with ASD. However, some people with ASD could find sexual activity challenging due to difficulties in tolerating physical affection (Kerr, 2007). This could lead to many people with ASD choosing to be sexually abstinent, (Simone, 2010).

When considering sexuality, the socio-cultural context needs to be taken into account as stereotypical perceptions on disability may form a barrier to sexual development in people with ASD. Murphy & Young (2005) argued that such perceptions may be more limiting than the actual disability, as stereotypes of disability render affected individuals as childlike or a-sexual and other people's expectations of those with ASD could become self-fulfilling (Rosenthal & Jacobson, 1968). This brings into question the nature of the way in which disabilities are viewed and contextualised within a greater socio-political context as it holds implications for the individual's self-perception. Liggitt (1997) captured this phenomenon by stating: 'Interpretations do not exist separately from the practices of social life. Instead they are embedded in systems of meaning, which are our social life. Because definitions are part of constitutive practices, definitions do more than just 'label' people. They constitute identities and in so doing, participate in the maintenance of relations of dominance' (p 3).

The above section highlights the need to be mindful of assumptions made about people with ASD and how such individuals could experience their sexual identity. There are various and prominent individual and contextual factors that could inform the sexual identity and affect the sexual experiences and preferences of an individual with ASD.

2.10 Conclusion

ASD is a disorder marked by significant social challenges. Despite these challenges the literature reviewed suggests that people with ASD retain the need for and desire to engage in social relationships as well as intimate relationships. There is some suggestion that receiving a diagnosis can be helpful in terms of supporting individuals and others around them in order to understand their functioning and adapt accordingly. However, having ASD and the increased awareness that comes with the diagnosis, has far reaching consequences for the ability to relate to others and is likely to pose a particular difficulty given the complex nature of intimate relationships.

Limited research exists regarding gender differences in people who receive the diagnosis of ASD in adulthood and how the diagnosis impacts on their social lives, relationships and other adult roles such as being a mother or a partner. A lack of sound knowledge in this area makes it challenging to determine how best to support individuals with ASD in a counselling context, thus giving rise to the need for the current study. The current study will therefore aim to explore the experiences of intimate relationships in a sample of women who received a diagnosis of ASD in adulthood.

CHAPTER 3: Methodology and Method

This section aims to provide a clear justification for the methodology chosen and consequently the method used. It will encompass the overall aim of the project, the justification of the research and its design. This will be followed by a section on methodology and the method of gathering data and the analysis thereof. The chapter will conclude with the ethical considerations taken into account before embarking on the current research.

3.1 Aim

The aim of this Research Project is to explore the experience of women who have been diagnosed with Asperger's Syndrome (ASD) in adulthood. In particular, the study aims to explore the responses to the diagnosis from the participants' point of view, with specific reference to intimate relationships. For the purpose of this study intimate relationships are defined as having been on several dates with someone which resulted in sexual activity, or with the potential to become sexual.

3.2 Scientific justification for the research

A better understanding of diagnosed persons' responses and adjustments to the diagnoses is likely to have practical implications for clinicians who help women with ASD to make sense of their condition.

It is hypothesised by the current author that a formal diagnosis of ASD may impact upon the diagnosed persons' (and their partners') expectations of intimate relationships. However, the specific nature of this impact is unknown and as yet unexplored in the empirical literature. Both clinicians and patients could benefit from an awareness of a patients' potential responses to a diagnosis and how it may impact upon their intimate relationships. This will support the provision of appropriate information and post diagnosis counselling to people with ASD which could include family and couples counselling. The study will thus be of interest to both the clinical and academic communities who work with people with ASD.

3.3 Methodology

This section will offer the theoretical underpinnings in which the method of data capturing is contextualised and the subsequent analysis thereof.

Epistemology refers to the nature of knowledge claims/conceptuality about the world. The Webster's Dictionary (1954) refers to epistemology as 'the science which treats knowledge in regard to its nature, limits, validity and grounds upon which is based; the theory of cognition'. To summarise, it is the theory of knowledge and a search for what and how we can learn or come to know about knowledge. Finlay (2006) stated 'our epistemology defines how we conceptualise the nature and status of our research enterprise' (p 18). An epistemological position is taken regardless of whether the researcher is aware of it or not (Finlay, 2006). Therefore, an awareness of the current author's own epistemological stance will to some extent shape the epistemological stance in the research. In turn, by the current author being transparent about her epistemological stance, it allows the reader to acknowledge and consider that the data will be informed by the current author's perspective. It is important to be mindful that the data is presented from a certain angle, of which there may be many angles. On this basis the current author's experience of the data will also be communicated in the analysis. This process is perhaps best captivated by Gadamer (1975/2004) when he stated: "Every finite presentation has its limitations. We define the concept of 'situation' by saying that it represents a standpoint that limits the possibility of version. Hence an essential part of the concept of situation is the concept of 'horizon'. The horizon is the range of vision that includes everything that can be seen from a particular vantage point" (p 269).

The current author's personal understanding of experience is embedded in the work of Friedrich Nietzsche and Søren Kierkegaard. Kierkegaard and Nietzsche both emphasise the view that every person has a unique subjectivity (Warnack, 1970). Both these philosophers imply that we live in a neutral environment and by our own subjective value system we add value calling it the truth in order to manage and manipulate the world in an attempt to find security (Warnack, 1970). The illusion creeps in when one finds this self-imposed value system and social ranking mistaken as the absolute and is deemed objective. From this perspective, subjectivity should be embraced. Spinelli (1989) stated that reality is the external world that will carry on even though the individual has passed away, while the interpretation of the external reality is more complex and will be filtered through the individual's mental process and 'in particular to our in-built, innate human species to construct meaning' (p 6).

A *Constructivist Interpretative* paradigm for the research would therefore be congruent with the current author's personal understanding and experience. It is also a paradigm which is frequently used in phenomenological and narrative research (Finlay, 2006) as it recognises the 'possibility of multiple meanings and subjective realities' (p 17). This approach can also be understood by contrasting it to objective realism which aims to find objective absolute (Finlay, 2006; Langdridge, 2007). This is not to say that enquiring about individual experience is not relevant. The aim is to give the reader an awareness of how a phenomena could be experienced.

However, despite the current epistemological position being as described above, it is still important to be mindful that the current study can be viewed from a variety of perspectives. Choosing a single epistemological position will allow for a more transparent and clear perspective from which to view the data (Holloway & Todres, 2003 p 355). Therefore, the current study will be underpinned by a *Constructivist Interpretative* epistemological position.

3.4 Method

This study will utilise a qualitative research method and aim to provide an in-depth description of the experience of women being diagnosed with ASD in adulthood.

Howitt & Cramer (2011) offered a number of circumstances under which, in social sciences, the use of a qualitative method of research is more appropriate than quantitative research. These circumstances include: a lack of research into a particular research topic, and when aspiring to understand something complex in a natural setting. Both these circumstances apply to the current investigation.

3.4.1 Phenomenology

The phenomenological method requires of the therapist to encourage descriptive statements, the withholding of significance and the holding back of theory (Spinelli, 1989). Therefore, the aim of phenomenological psychology is to 'study the experience and how the world appears to people' (Langdridge, 2007 p 5) and according to Milton (2005) 'provide a description of an individual's reality beyond formal theory and therefore accommodating for the possibility that a phenomena might

have multiple meanings for an individual'. Therefore, it could be concluded that this methodology lends itself well to the current study which aims to focus on the experience of intimate relationships of women with ASD. It is also congruent with the particular epistemological stance of the researcher. Phenomenology can broadly be divided into Descriptive and Interpretative Phenomenology.

3.4.1.1 Descriptive Phenomenology

Husserl referred to Descriptive Phenomenology as the natural attitude being the process which precedes the understanding of an object for its true essence (Langdridge, 2007). Thus, in descriptive phenomenology the researcher attempts to see an object for its true essence by suspending or bracketing pre-existing knowledge (Willig, 2009). While this appears logical as it could provide a more untainted analysis, it is in contrast with the epistemological position of the current author. On this basis, the descriptive phenomenological methods were deemed to be not appropriate for the current study.

3.4.1.2 Interpretative Phenomenology

In Interpretative Phenomenology, the position is taken that one cannot delineate the description of a phenomenon from an interpretation thereof (Willig, 2009). This means that the experience of the participant is furthermore interpreted by the current author when described in the research. It is at this point that reflexivity on the part of the current author becomes significant. The data is viewed as the participant's experience of a conglomerated expression of her culture, sociality, history and language (Finlay, 2006) whilst being mindful of these factors in the current author's own life which may influence the subjective position of interpretation. This means no two interpretations of the research can or will be the same and the findings are contingent upon the context in which the research is conducted, i.e. by whom is the research being done.

Adopting a phenomenological attitude therefore involves reflexivity as the focus shifts to the experience of objects as opposed to the actual object (Smith et al., 2010). Therefore the reflectivity, in part, can account for the researcher's prejudices.

In light of the above differentiation, it is concluded that an interpretative phenomenological approach is perhaps more in line with the epistemological position of the author than a Descriptive Phenomenological Approach.

3.4.1.2.1 Considering different types of Interpretative Phenomenological approaches

Interpretative Phenomenology could employ the following methods to understand the data: Hermeneutic Analysis, Template Analysis and Interpretative Phenomenological Approach (IPA) (Langdridge, 2007).

In Hermeneutic Analysis the focus is also on understanding the meaning of experience. However, it is a drastic move away from a search for essence to the extent that the method does not prescribe a clear procedure to follow when analysing the data (Langdridge, 2007). The rationale is to allow an individualised approach where the current author can contribute to the research freely, which will result in the research being a co-production of interviewer and participant (Langdridge, 2007). This co-production results in themes emerging out of 'the relationship between the researcher and the text' (Genz, 1996 cited in Langdridge, 2007). Hermeneutic Analysis aims to reflect the current author's interaction with the participants. As the scientific justification for this study highlights, the study aims to capture themes which may inform the direction of future research. Therefore, IPA was deemed more appropriate.

Template Analysis requires the researcher to make use of a start-list relevant to the data that is being collected (Dickie, 2003). Reynolds (2003) used both IPA and the Template method in a study concerning the meaning of artistic occupation for women who are living with a chronic illness. Reynolds (2003) concluded that of the two methods, IPA was more desirable when conducting the study as IPA resulted in a more in-depth understanding of the phenomena.

In addition, other types of qualitative analysis were also excluded on the following basis: Grounded Theory (Glaser & Strauss, 1967) which is directed towards generating a theory, and Narrative Analysis (Sarbin, 1986) which focuses on the content and the language used to describe experience. However, the aim of the current study is not to understand how women with ASD make sense of intimate relationships but rather how women with ASD experience intimate relationships. IPA is often used as methodology in researching psychology and health disciplines for its ability to capture the intricacies of experience (Reid et al., 2004). The approach invites participants to share their own experience of a phenomenon being investigated by the researcher (Willig, 2009), while providing the researcher with systematic steps to accommodate the interpretation of the phenomena (Smith et al., 2010). This in turn supports the researcher to balance interpretation with description and to perhaps draw own conclusions about the data presented. The IPA method allows the researcher to

produce an interpretation of the participant's experience, which goes beyond the language they used, with the aim of interpreting their statements (Smith, 2004 cited in Larkin et al., 2006 p 113 - 114).

IPA has been critiqued for not having enough validity because it does not produce results which are replicable. On this basis, Giorgi (2011) disregards IPA as it does not meet the criteria for being a 'scientific method'. Although this may be the case, the current study attempts to address this criticism, by providing a clear and transparent epistemological stance which will allow the reader to be able to trace the interpretations made from the data.

I chose to conduct analysis of the transcripts using a stepwise, systematic approach, which allowed me to stay close to the original experience and the statements of the participants. I did this to mitigate the critique IPA has also received for not always being fully transparent; in that the method relies too strongly on the researcher's interpretation (Giorgi, 2010 p 3 - 22). In addition, IPA is not blind to the importance of language as the method acknowledges that a participant's ability to describe and narrate their experience is dependent on language. The language used is dependent on the language available to the participants to describe their experiences. It is acknowledged that participants' use of language could be different to that of the current author. Therefore, it is acknowledged that the participants and the current author may have different levels of familiarity with, and accessibility to the constructs that the participants communicated.

In addition, the current author is mindful that by using this method, the ability to generalise the findings of this research may be affected. This issue will be further addressed in the Discussion chapter where the data within the context of the strengths and limitations of this research, will be discussed.

Despite the above criticisms of IPA, it is still considered the most favourable methodological approach for this study because the interpretative focus reflects the current author's own epistemological stance: interpretation is inevitable when trying to convey another's experience. The current author acknowledges that she can only make sense of it from her own (inevitable) subjective position.

3.4.2 Process of collecting data

3.4.2.1 Sampling and inclusion criteria

Previous studies of the experience of people with ASD used relatively small sample sizes. Howard et al., (2006) documented the experience of one individual while Muller et al., (2008) investigated the social experiences of eighteen individuals with ASD. Punshon et al., (2009) documented the experiences of ten participants.

Smith et al., (2010) suggested a sample size of three to six participants in a study utilising IPA: small, homogenous, well defined and purposively selected. This allows for an ideographic analysis as well as the identification of common themes. However, this could also result in the data being skewed and not representative of the total population group of women who have been diagnosed with ASD in adulthood.

As the population group is specific, purposive sampling was used to ensure that the participants were able to provide meaningful insight into the topic relevant to the research. Participating women were recruited to the current study via two streams. One stream was via diagnostic clinics in London (Islington and Newham) and the other via an advert on the National Autistic Society's website.

3.4.2.2 Inclusion criteria

Case selection was based on the following inclusion criteria:

- The sample consisted of women between the ages of 20 and 40. The age of 20 was chosen as the lower limit to allow for having adult experiences of intimate relationships. The upper limit age of 40 was chosen as it was hypothesized that women between 20 and 40 might be more homogeneous than those in a broader age range, and to allow for the sufficient numbers of potential participants.
- All of the women were in an intimate relationship or had experience of an intimate relationship (i.e. been on several 'dates' with the same person).
- The women had received a diagnosis of ASD within the last five years. This restriction on time since diagnoses, was made in an attempt to maximise homogeneity amongst the group.
- To ensure that each of the participants had sufficient understanding of the English language and to enable dialogue with the current author, it was required that the women had

received either secondary or tertiary education in English and obtained a minimum of one GCSE.

3.4.2.3 Exclusion criteria

- Participants were excluded if they were seeing a doctor for an active mental health problem (excluding ASD and associated problems) at the time of data collection. This was to avoid exacerbating any difficulties associated with co-morbidities and to ensure the results were representative of the experience of having ASD and not due to any co-morbid diagnosis.
- Participants who were not able to give consent or lacking capacity to give consent were excluded. This was to maximise the possibility of the participant giving a meaningful account of their experiences to the researcher. Capacity to give consent was assessed by appropriately qualified clinicians. For participants who responded to the advert on the National Autistic Society's website capacity was assumed as a result of them having been able to read and appropriately respond to the advert, including a self-assessment of their compatibility with the inclusion criteria. In addition, these participants were asked if they were currently under the care of a psychiatrist for difficulties not relating to ASD.

3.4.2.4 Participants

All potential participants were provided with information about the study (Appendix 2) and asked to contact the current author if they were interested in taking part. All eleven potential participants responded and subsequently consented to participate. Appointments were arranged with each participant. Nine participants attended their appointments. Upon follow-up, one participant stated that she was of the opinion that she did not have ASD and therefore withdrew her consent. The others declined the offer of an appointment.

The two identified recruitment streams resulted in useable data from eight participants who met the inclusion criteria. A full description of the recruitment process is depicted in Figure 1. A full description of the participants' demographic information is provided in Chapter 3.

Recruitment was restrained by the number of willing and available participants given the time frame. A year was allowed to recruit, interview and analyse the data. It proved difficult to recruit participants. It is hypothesised by the current author of this study that this difficulty could be

ascribed to many contributing factors including: women with an adult diagnosis of ASD are a much smaller population group in comparison to men who received the diagnosis in adulthood. In addition, the exclusion and inclusion criteria limited the number of suitable participants for the study. Finally, perhaps by the nature of the diagnosis, these participants might have it particularly difficult to interact with a stranger (in this case the researcher herself).

3.4.3 Interviews

In order to facilitate the participants' accounts of their experiences, the interviews were conducted face-to-face. This enabled both parties to fully explore the meaning of the questions posed and to elaborate on the responses immediately. One-to-one interviews are considered compatible with the IPA approach (Smith et al., 2010). Semi-structured interviews involving a series of open-ended questions (Appendix 2) were used to collect data. This type of interview and questions allow for a balance between consistency and flexibility (Smith et al., 2010). Consistency was considered important to support the provision of specific topics for discussion. However, flexibility was required to allow for the ideographic nature of the lived experience.

Furthermore, the semi-structured questions were carefully constructed in order to avoid leading questions as the integrity of the study depends on the subjects' responses not being unduly influenced. After the initial interview, the schedule was discussed with the research supervisors and adjusted for the subsequent interviews. Consequently, the questions were framed within the primary research aims and specified, following discussions, about what would be likely to elicit useful and relevant discussion with research supervisors and colleagues. This was aimed at strengthening the focus on the specific research question.

All but one interview was conducted in the participant's home and this one was conducted in an office at the current author's training organisation. All the interviews concluded with a debrief (Appendix 4). All the interviews followed the procedure detailed in Figure 1.

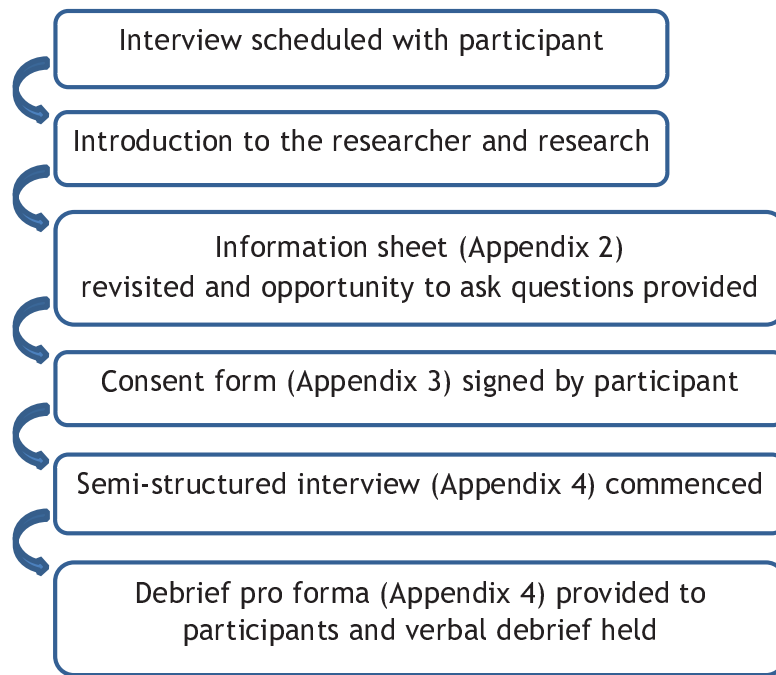


Figure 1: Interview procedure

3.4.4 Process of the analysis

The interviews were transcribed verbatim, anonymised and analysed in line with the six steps of IPA Analysis as described by Smith et al., (2010). Step 1 was to become familiar with the case by reading the transcript several times. Step 2 step involved making descriptive, linguistic and conceptual comments on the text. The descriptive comments were comments relating to what the participant was saying without any interpretations of deeper meaning. The linguistic comments referred to the way in which she said something and possible functions of her language. Conceptual comments were underpinned by both the linguistic and conceptual meaning in order to facilitate a deeper interpretation of the possible meaning and the generation of questions about the participant's sense making. Step 3 involved the identification of emerging themes which were recorded as they came up. In Step 4, the connection between the emerging themes was established to allow for the identification of possible super-ordinate themes. Step 5 involved moving onto the next case and Step 6 involved the identification of conceptually similar themes between cases. Table 1 depicts the process of the analysis.

<i>Connected theme</i>	<i>Emerging theme</i>	<i>Interview</i>	<i>Para no.</i>	<i>Personal reflection</i>
Thinking about dating	Reason to date: social pressure/ wanting to be part of the norm	GRETE: None! L: Okay? GRETE: Well, I went through the motions when I was younger by having boyfriends and I never got turned on, never... I wanted to be normal and be like everyone else...	2	She seemed to give the impression that her interactions with him were driven by external factors rather than internal needs and wants.
Sexuality and sexual experiences	Experiences self as a-sexual	...and I was born without sexual feelings, a bit like this famous Autistic lady - what's her name, the one who registered the cow machine - oh, what's her name - but she hasn't got sexual feelings either. So It's not uncommon: a lot of people with Autism do have sexual feelings but some people with Autism were born without them. L: Yeah? GRETE: So I've been a-sexual all my life... which means I'm not interested in men or women. L: Are you interested in relationships?	3	I wondered if this was been a response to the diagnosis.
Sexuality and sexual experiences	Sexuality: preference for more platonic relationships	GRETE: Platonic ones... I'm interested in... I have a good relationship with the Rabbis who is the Rabbi's wife and I have a very good relationship with my life coach and they seem like elders.	4	She communicated the type of relationships she preferred and how the possibility of sex informed her relationship.
Sexuality and sexual experiences	Sexuality: preference for more platonic relationships	But when people are like... in just pairs... it doesn't... it is not normally good, but I just don't normally show an interest in that side of things - I just want to be looked after.	5	

Thinking about dating	Reasons for not dating: does not have the time to date	So normal relationships - I haven't got an interest in them, simply because... when I go to the Group I see everyone in the Group and show that I'm pleased to see them but when I'm outside the Group, because I'm so busy doing my own things like my gym, and go to my own groups and do stuff around the flats like catching up on things around the flats - things like that. So I don't really have time for people...	6	Possible ASD trait – inflexible thinking, consequently keeping to routine without prioritizing. (Reminiscent of the issues we had when I tried to arrange a meeting with her.)
Experience of relationship	Concern about the natural progression in relationships	L: Do you like spending time with people? GRETE: I do like people... like the relationships I have with elders like with the Rabbi's wife and my life coach because they look out for me and they're helping me move to London, and also because I like being around them... like paternalistic and maternalistic... so I like that kind of relationship whereas pair relationships where it's all equal and you look after each other - I'm not very good at looking after someone else, I'm afraid. So no it would not work.	7	The doubt could be an obstacle to forming romantic relationships.
Thinking about dating	Barriers to dating: belief that no one makes an effort with her	L: Did you always feel this way? GRETE: When I was 21, so it was in... I got it many years ago. I do like to have friends but it never works out... like they string me along and it's... we'll see you later and they never do... or I'm too busy for them, or I haven't seen them in a long time and they don't make the effort. Same thing happens in when I have been in a pair.		This could be a barrier to dating but it also indicative of something about the sustainability of relationships. In this instance she is communicated it as being a barrier to future relationships.

Table 1: The process of the analysis

3.4.4.1 Reflectivity

As awareness of the inter-subjective under-currents is key to the integrity of the research, it was important for the current author to become aware of how her 'own social background, assumptions, positioning and behaviour affects the research' (Finlay, 2006 p 21). This formed the basis for understanding the subjective viewpoint.

Langdridge (2007) referred to reflectivity as "... the process in which researchers are conscious of and reflective about the ways in which their questions, methods and very own subjective position (as white/black, middle class/working class, heterosexual/homosexual, insider/outsider etc.) might impact on the psychological knowledge produced in the research study" (p 58 - 59). Therefore, the process of reflectivity does not attempt to bracket the current author's assumptions or biases, but rather to make it clear that the data is a representation of how the current author's own experiences, values, and positions of privilege in various hierarchies may have influenced her research interests; the way in which she chose to do the research, and the ways she chose to represent the research findings.

The current author of this research study was mindful of the interpretative nature of qualitative research and that the findings of the study would be a co-construction of participants' experience and her own interpretation thereof.

An awareness of the current author's own subjective position in relation to the research question is of key importance as it shaped her subjective position and understanding of the participant's material. The position the current author took was largely formed by her own experience, knowledge and understanding gained from working in and studying the field of psychology. In addition, the current author shared many of the features of the participants: being a woman, being in the same age range of the participants, and having experience of intimate relationships. These roles (woman, a partner in a relationship and a scholar in psychology) informed and shaped her perspective on the participants' experience.

The current author kept notes on her experience of meeting with the participants, her impression of the raw data and engaging with it. This allowed for reflection on the assumptions made, values and the conclusion she was drawing. An example of a reflective thought process is provided below:

A participant wanted more direct guidelines from her partner on how to respond to him. The current author felt perplexed as it did not fit with the dynamics in her (the researcher's) own personal relationship needs. The current author reflected upon her own assumption that a key value of intimate relationships was the spontaneous nature thereof. The current author also found herself considering, based on professional knowledge and training, whether or not the participant could reduce her anxiety about how to conduct and maintain relationships if she had more specific guidance. Being reflexively aware of the tendency to apply both her personal values and professional judgement, allowed the current author to be aware that there might be more than one meaning to how the participant tried to make sense of her experience.

3.4.4.2 Validity

Yardley (2000, 2008) outlined four essential principles for ensuring validity of the phenomenological account in qualitative research. These are:

1. Sensitivity to context
2. Commitment and rigour
3. Transparency and coherence
4. Importance and impact

Principle 1 is demonstrated in the current phenomenological interpretation through the provision of specific examples from the raw data alongside any conclusion drawn. Principle 2 is ensured by the rigorous selection of samples and the outlining of the current author's epistemological stance from the outset. Principle 3 has been achieved through the provision of clear information regarding the current author, the participants, the analytical process and the phenomenological account of the current author's experience of the data. This allows for the reader to make an informed conclusion regarding the plausibility of the phenomenological account. Principle 4 was ensured in the first instance, following discussion with research supervisors regarding the likely importance of research that would be founded on the aims of this study. This principle will be appraised on an on-going basis by readers of the account; - according to their judgement of the importance of this research and the utilisation of the phenomenological account for academic or clinical purpose.

In addition, supervisors reviewed the quotes to ensure that these were grouped together in a coherent way and that the theme names are representative of the grouping.

3.5 Ethical considerations

Ethical approval has been obtained from the NHS as well as from the academic institute overseeing the research (Middlesex University). The risk to the participants and the researcher are summarised below. The full NHS ethics application is enclosed (Appendix 1).

3.5.1 Risk to participants

The potential risks and burden to participants were minimal. All participants were given an information sheet (Appendix 2) which outlined the nature of the research, and the aims and objectives prior to commencement of the research. The interviewer then explained the procedure and the purpose of the study prior to obtaining written consent to participate. Participants were made aware that they would be asked about intimate relationships.

Participants in the study consented independently to their voluntary participation by signing the consent form (Appendix 3), and were informed that they could withdraw from the study at any stage.

Participants' health was not affected by their participation. In addition, participants were told that they were not obliged to answer any questions which made them feel uncomfortable. Furthermore, the interview schedule started with open, general questions before progressing to more specific probes. Probes were only based on the material participants offer. Questions were designed to be non-intrusive. This allowed participants to decide how much or how little to reveal. Participants were reassured that they were free to end the interview at any time and that the researcher had a duty to seek help if the interview revealed significant concerns.

If the participant had disclosed something that required action, she would have been directed towards the service centre which initially informed her of the study, i.e. Camden and Islington Foundation Trust or East London NHS Foundation Trust. For example, safeguarding issues would have been dealt with by these teams.

3.5.2 Risk to researcher

The research was conducted in a professional setting or in participants' homes if usual clinicians had deemed it to be safe. With access to help if required, it was considered that there was a low level of risk for the current author.

In instances where the interview was conducted in a home of the participant, a risk assessment was conducted and the necessary precautions were followed.

The above section depicted the methodology and method for gathering the data. The synopsis of the interpretation of gathered data will be covered in the next section.

CHAPTER 4: Results

4.1 Introduction

Interpretive Phenomenological Analysis (IPA) was conducted on the transcripts of all eight participants. The current author identified four overall themes in the analysis of the data. These themes were: Response to receiving the diagnosis and information about ASD; Factors influencing the decision to date; Experience of relationships as a person with ASD and lastly, Sex and sexual experiences. Each of these themes have several sub-themes. Whilst the major themes encapsulate the commonalities between all participants' accounts, areas of divergence emerged. These have been commented on where particularly relevant to the research question. The overall themes and associated sub-themes are depicted in Figure 2.

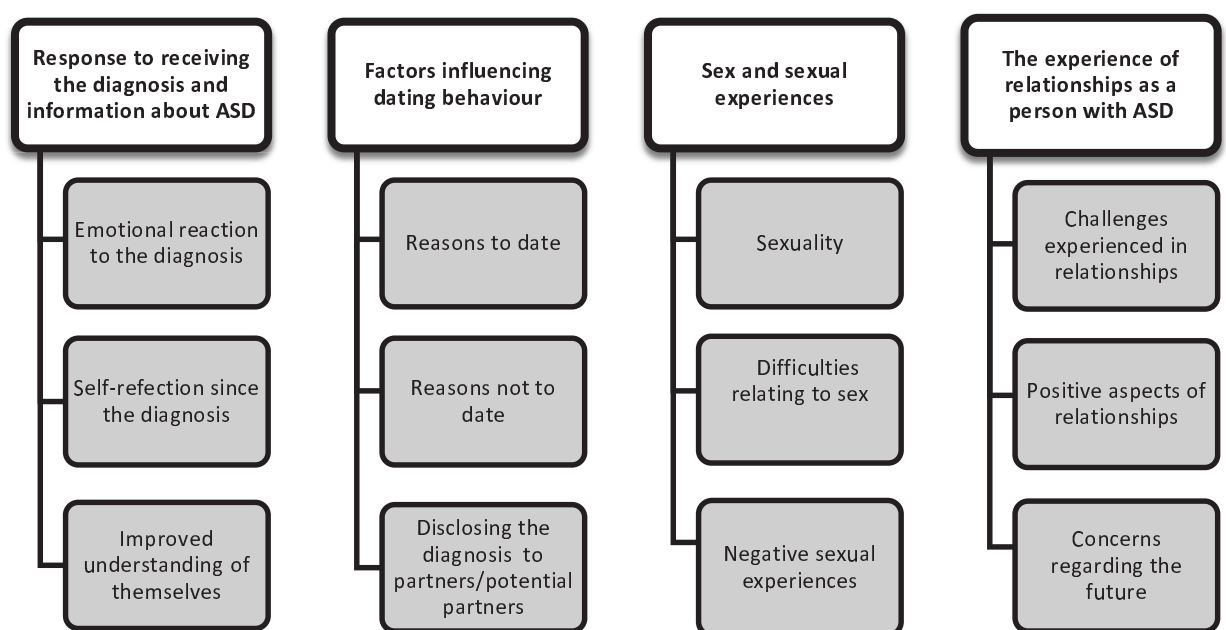


Figure 2: Overall themes and associated sub-themes

This chapter will present each of the identified themes and their associated sub-themes, alongside illustrating quotations taken from the interviews. It should be noted that the quotations provided were chosen to illustrate points relevant to the research question and therefore, are unlikely to cover the full extent of participants' experience of relationships. Additionally, whilst not all of the

provided quotations infer direct references to intimate relationships, they do largely cover various aspects of the experiences of interpersonal communication - an essential building block for successfully establishing an intimate relationship.

Most of the quotations are presented verbatim as described by participants during the interviews. However, where changes have been made, for ease of readability, these are indicated by square bracketing. Dotted lines before or after a quotation indicate that the provided words were part of a longer sentence or period of speech by the participant. Where participants used names of their partners, these have been changed to preserve anonymity. An interview, transcribed verbatim, is enclosed in Appendix 5. Eight participants in total took part in the current study. Brief demographic information regarding each participant is provided in Table 2.

<i>Participant</i>	<i>Participant age at time of study</i>	<i>Relationship status at time of study</i>	<i>Participant's description of her sexuality</i>	<i>Recruitment source</i>	<i>Children</i>
Participant 1	40	In a long term relationship	Heterosexual	Newham NHS Trust	No
Participant 2	26	In a new relationship	Heterosexual	National Autistic Society	No
Participant 3	38	Single	Asexual	National Autistic Society	No
Participant 4	24	Long term relationship	Bisexual	National Autistic Society	No
Participant 5	37	Married	Heterosexual	National Autistic Society	Yes
Participant 6	35	Single	Bisexual	Camden and Islington NHS Trust	No
Participant 7	26	Single	Bisexual	Camden and Islington NHS Trust	No
Participant 8	27	Divorced, currently single	Bisexual and 'demi-sexual'	Camden and Islington NHS Trust	No

Table 2: Demographics of the participants

4.2 Response to receiving the diagnosis and information about ASD

This theme aims to capture the feelings and experiences recounted by participants following a diagnosis of ASD. All eight participants reported on aspects of their response to receiving the diagnosis. However, they spoke about their experiences in different ways. Therefore, this theme has three sub-themes which include: emotional reaction to the diagnosis, self-reflection since the diagnosis and improved understanding of themselves (see Figure 3 below):

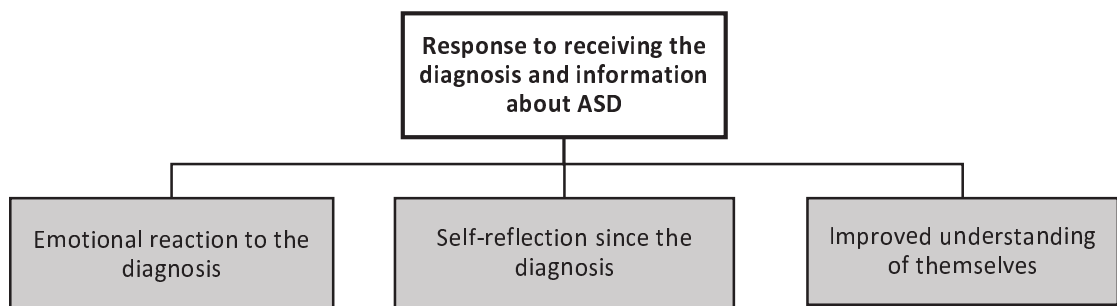


Figure 3: Response to receiving the diagnosis and information about ASD

4.2.1 Emotional reaction to the diagnosis

Five participants spoke of their own emotional reaction to receiving a diagnosis of ASD. This revealed a variety of emotional responses ranging from relief and being pleased about receiving the diagnosis to grief, hopelessness and self-doubt.

Three participants described how they felt relief at finally having an explanation for some of their difficulties:

“I wasn’t just someone who had something wrong with me... there was a name to it which explained why I was the way I was and the way I am and there was a meaning to the way I was.... there’s nothing wrong with me... I’ve got this condition. In fact, I’ve got five t-shirts I’ve had specially made: one says I’m Autistic and proud; one says I’m Autistic – what’s your problem?; one says It’s called Autism – look it up; one says My Autism is my gift, not

my disease; and what does the fifth one say... what's the fifth one... My Autism makes me different, not less..." (Participant 4 para 24).

"...there finally was a reason to everything I didn't know...felt relieved" (Participant 4 para 46).

"Relief to finally say this is what it is, this is why years of counselling haven't worked and this is why..." (Participant 7 para 46).

"... [I] kind of always knew everything wasn't quite... not right... like stuff... I wasn't like the rest of my like tiny group of friends... so it was a relief when I did get the diagnosis because it's like okay, I understand why I do this, this and this while everyone else does something different..." (Participant 3 para 8).

"... it was good and it was kind of good to say - okay teachers, mum, friends, whatever, this is what I have, like this is why I do these things... like if you are unsure, you can go and read up on this... like it's not that I don't like you or whatever, it's why I act this way" (Participant 3 para 9).

One participant implied that she felt relieved to receive an ASD diagnosis as opposed to a mental health diagnosis:

"... because I have been told I have mental health problems [in the past]. I thought difficulties of Asperger's were just, well just me being crazy, I thought it was just me being crazy!" (Participant 2 para 23).

To another participant the relief in receiving the diagnosis provided her with a reason as to why the treatment she received for mental health related difficulties before the diagnosis of ASD, had not been effective. In addition, to some extent her quote below communicated a sense of accepting ASD related difficulties as inevitable:

"Relief to finally say this is what it is, this is why years of counselling haven't worked and this is why... all these techniques I've been shown for panic attacks and anxiety disorders. It's not an anxiety disorder. It's not a panic attack. It's a meltdown and there's no way to stop it. It's like a tornado, once it starts, it can't be stopped" (Participant 7 para 47).

Two participants described receiving the diagnosis as a joyful experience. Participant 1 perhaps had an even stronger positive emotional reaction to her diagnosis - describing that she felt thrilled:

“Initially when I got my diagnosis, I was so thrilled. I was going around telling everyone. Because before then, I was wondering, why me, why do people pick on me, why am I always picked out” (Participant 1 para 74).

Not all participants reported a positive emotional response to receiving their diagnosis, suggesting a possible continuum of emotional responses. Five participants had less positive emotional reactions to receiving their diagnoses. Participant 5 highlighted that she experienced a sense of grief when learning about her diagnosis and realising that no matter the amount of effort she put in to her current long term relationship, she was unlikely to be able to overcome her difficulties. This response to the diagnosis seemed to be reflective of a different interpretation of the meaning of the diagnosis - she appeared to have lost hope that she could be helped:

“Which is, you know... is... this is a form of grief in that I thought: oh my goodness, all the techniques I so tenaciously tried... you know, researching this, researching that and tried to do all the things to make him feel better... I kind of tried... and tried to keep the house, and do things I know how to do, try to create a nice environment for him because a nice environment makes me feel secure but I’m actually not a very empathetic person. I never was because I wouldn’t know how to do it!” (Participant 5 para 106).

The same participant described feeling hopeless. This was related to her perception of her inability to help her partner through a difficult time:

“... I tried and tried and tried and now I know I was never going to be able to have helped him... and the one thing I find really gutting about the diagnosis, is for all I tried, there actually wasn’t a hope of actually being able to do it” (Participant 5 para 106).

In discussing their responses to the diagnosis, three participants shared more complex reactions perhaps indicating that they experienced more doubt in their own judgement of situations since they were now aware that there could be alternative ways of interpreting a situation. Participant 5

talked about how she struggled with the new realisation that there could possibly be more accurate explanations for any given situations than her own:

“At first it took the wind out my sails... because actually the foundation and everything I thought was so obvious to me... because if it was obvious to me, it was obvious. Now I’m thinking... ah, perhaps I wasn’t right about that, perhaps I was wrong. A bit like a platform coming out from under my feet, and I’m suddenly thinking from under the stage: oh dear, you know... I used to trust very strongly in the evidence before my own eyes, and now I don’t” (Participant 5 para 27).

Perhaps also related to the experience of self-doubt, Participant 6 described how she worried about ‘getting it wrong’ more since the diagnosis and this had been a struggle for her. This seemed to be a reflection of her having only recently realised that there could be alternative perspectives other than her own experience of social interactions or situations, and that initial impressions were not always accurate or conclusive:

“...there’s definitely been a lot of worry about getting it wrong, more since the diagnosis. There’s a lot more sense of awareness... things that I might be wrong about. My feeling is that I should do this and then this is... kind of like.... my instinct isn’t right...” (Participant 6 para 60).

“I might have felt like what I knew about it, might have been the right information or it was ok, but now I feel a lot more doubtful about that kind of stuff and I kind of think it makes it kind of harder to negotiate in those sorts of territories in a lot of ways...” (Participant 6 para 61).

Participant 1 reported that receiving the diagnosis had caused her to become more socially inhibited as a result of being less trusting of her own judgement. For example, this participant described feeling scared of making social mistakes in her communication with, or judgement of, others. This led to her reflecting on her own reactions to situations and questioning the validity of her instinctual responses:

“Well, socialising is always a disaster. But now that I know about the social anxiety and inappropriate side of Asperger’s, in general it inhibits me a little more. Scared of making a social mistake...” (Participant 1 para 70).

“I went to a pub with Stanley and there was a table here... two people were loudly kissing, like this – wet sounding kisses and snuggling – and me, I was thinking get a room! I felt very uncomfortable! Like some kind of voyeur! You see couples giving hugs and kisses in public but these guys were doing what Stanley and I do in three hours, in five minutes! ... I felt so uncomfortable! I’m never comfortable with it. Sometimes, yes – but sometimes I’m a little more aware that it could be the Asperger’s. Sometimes I’m sitting there thinking if that’s normal [to others] because I feel uncomfortable... is it only me [because I have ASD] or is it just uncomfortable for everyone” (Participant 1 para 71).

4.2.2 “I’m not an alien...” - Self-reflection since the diagnosis

Six participants spoke about how they viewed themselves since receiving the diagnosis. Five of them described how they had developed a greater sense of self-acceptance and confidence as a result of receiving their diagnosis.

Several participants reported that they experienced receiving the diagnosis as positive, helping them to be more confident:

“Affirming I guess. Just the idea that I don't have to hide it...” (Participant 6 para 28).

“So getting the diagnosis I suppose made me feel more confident” (Participant 8 para 43).

“Yeah... [since the diagnosis] I’m more comfortable with who I want to be and who I am... and I can like say to people if they say something that isn’t very nice - give a reason to them for why I am the way I am” (Participant 3 para 17).

Participant 2 explained that having received the diagnosis and subsequent information about the nature of her difficulties enhanced her confidence. This was because she was able to understand that the difficulties she experienced were not simply due to her being deficient in some way. Consequently she became more accepting of herself:

“Confidence... yeah... acceptance would probably be the right word. Some sort of self-acceptance. Because I suppose I’ve been thinking of myself as lacking and wanting to improve loads of aspects of myself” (Participant 2 para 28).

“Thinking I just have to... stop being such a wimp about noises and just get on with it” (Participant 2 para 29). “...and not constantly seeing yourself as deficient in some way. That alone helps” (Participant 2 para 31).

“But now I can say hang on, you might not be able to. You might just need to structure your life in a way that you can avoid some of the challenges rather than thinking I have to man up to them” (Participant 2 para 30).

Participants 2 and 7 talked about how coming to accept themselves had a positive influence on their interpersonal relationships. This seemed to be through a process of being less self-critical:

“It [the diagnosis] probably has actually helped me to come to terms with myself a bit more and I think in a non-direct way, that will help me in terms of relationships because you feel a bit more easy about yourself or you come to terms with aspects of understanding yourself and helps your doubts...” (Participant 2 para 24).

“I sort of... before the diagnosis I wouldn't even entertain the possibility, it was just no, life is too hard, my brain is working too hard already. Having someone that close, no, that's not gonna happen. And then, I got the diagnosis and it's like, ok then you can talk. I don't have to be turned on all the time. It is ok to say I'm overwhelmed and if it's ok to say those things then maybe it's ok to maybe think about maybe in the future there might be someone I can just be me with” (Participant 7 para 97).

Two participants elaborated on when they initially suspected that they had ASD, they started to talk to others, who had similar difficulties, about it. Consequently, this helped them to develop an understanding that they were not alone, which also implicated the way in which they viewed themselves. In fact, to some extent they normalised their difficulties when contextualising them within the context of the diagnosis:

“I will admit that I started suspecting about Asperger’s about a year before I got the diagnosis, which is part of the reason I asked for a diagnosis or asked to go through the procedure just to see... but it [the nature of ASD] started to clarify an awful lot of things. Especially when I spoke to other people, other women in particular on the spectrum who already had the diagnosis. Because I discovered there were all these idiosyncrasies I have that they'd share” (Participant 6 para 11).

“And no I'm not the only one, it happens to other people. I'm not alone, I'm not an alien, I haven't been dropped here from another planet. I'm just different. That's ok, there are other people that are different, it was relief” (Participant 7 para 47).

4.2.3 “I can’t read your eyes because I have Autism” - Improved understanding of themselves

Six participants spoke about how they understood themselves better and improved awareness of the nature of their difficulties as a result of having received the diagnosis, and more information about ASD. It seemed that the ASD diagnosis provided an explanation for some of their identified traits, difficulties and behaviours.

These participants described how having an overall improved level of understanding, as a result of their diagnoses allowed them to explain to others the reasons behind certain interpersonal behaviours. Participants 1, 3 and 4 explicitly stated that as a result of receiving the diagnosis, they were able to provide others with a rationale for their behaviour:

“Yeah, it was a very positive experience. I can explain to people - I can’t read your eyes because I have Autism - but before I didn’t know that I couldn’t read eyes and I couldn’t understand why everyone else could follow me, but I couldn’t follow them. You see, Dan [the clinician who diagnosed her] explained everything to me and it’s helped me articulate my condition so that I can explain to people in a way that’s more like...” (Participant 4 para 48).

“... and I can like say to people if they say something that isn’t very nice - give a reason to them for why I am the way I am” (Participant 3 para 17).

“The Asperger’s thing... [receiving the diagnosis helped to] being able to talk about it with the guy I am seeing at the moment is helpful because I feel I can say, I don’t like this because I don’t want to do this, or that might be difficult, or this. It gives me and him a clear reason...” (Participant 1 para 83).

For example, Participant 2 described how since the diagnosis, she was aware that she could be ‘difficult’ in other people’s company due to the strain caused by being social and interacting with others:

“... I could be difficult and snappy at times or get distressed or very tired really, if I don’t have a break from people. Yeah, so it is a sort of self-awareness that came from it” (Participant 2 para 107).

Below is an example she provided of a time she felt tired by interactions. She explained a situation where she was expected to socialise with a friend over the period of a day and how this alone was trying. However, this feeling was compounded when the interaction involved more people:

“But by lunch time the next day - her parents were, well her parents were here as well – and I was getting quite tired and becoming a bit snappy and was thinking in my head: Mom, could you put Fiona away now please... and I actually went to bed and had a rest. It was bad because I had snapped at my dad about it... I was just really kind of being fed-up with being around people you know... break the routine so I was... I went to bed for a bit” (Participant 2 para 102).

Due to the awareness of her behaviour during social interactions, Participant 2 could describe this particular difficulty to her partner. The aim of describing it to him was to aid his understanding of her and to support him in not misunderstanding the intentions behind her behaviour:

“...but I have warned him: if I want to be on my own, if I don’t want to talk, it’s not a comment on you – it’s a comment on me needing rest... away from people but because it may be misinterpreted as not wanting to be around or a personal comment on him - and it is not. Or, if it was, I would let him know. It’s kind of... it’s all a bit much to handle” (Participant 2 para 105).

Another example of how some participants improved their understanding of themselves was provided by Participant 5 who, since receiving the diagnosis, reported that she had discovered the importance of using facial cues in communication. She described in detail the specific difficulty she had in understanding the importance of non-verbal facial cues and expressed her surprise that it had taken her so long to realise this. This is indicative of her improved insight into ASD and the associated difficulties:

“And I’ve really tried, you know. I tried studying... do the eyebrows go up a little when someone’s frightened (laughing)... This one’s really interesting: we were on a bus once with a baby sitting in front of us and the baby looked at me and I smiled – and the baby was horrified, and of course I said: I just smiled at the baby and scared it! And Paul said like: it’s in your eyes, you can’t just show your teeth and think that’s a smile. It’s just like that... you’ve got to do this with big eyes, and he did it with the baby and the baby went: ahhh, giggle, giggle! Really, have I got to do that? So I was trying to be sort of over theatrical and then we were sort of interacting. It took 37 years – I was 36 when this happened – it has taken me 36 years to realise I have to use my eyes as well” (Participant 5 para 74).

Some participants related their improved awareness of ASD traits more directly to their perception of social rules in dating. Participant 5 mentioned how she improved her understanding as a result of her diagnosis through attending counselling and reading literature. She concluded that men might actually like behaving in a certain way when dating and that her behaviour could contradict and prevent the successful negotiation with regard to relationships:

“Actually, I’ve only come to realise in maybe the last six to eight weeks part because of the diagnosis and part the counselling, I think from what I’ve read... not from what I’ve observed because I haven’t have observed it – but men probably do like to look after women and men probably do like to buy you dinner without you saying: I can buy my own. Maybe [when] they [referring to her partner] do like to buy you a gift and that you say [simply say]: thank you that was really lovely – because the thought counts. I was terrible when it came to gifts... awful! I’ve been awful...” (Participant 5 para 29).

Participant 8 appeared to be saying that she was aware that others might not perceive situations or dating rules in the same way that she did. However, she communicated that this had caused her to be apprehensive when she was managing the practicalities of dating:

“Like the gender stuff is something that I just really started to get my head around... if we order a pizza or something like that from my house and I rushed out to pay for it or something like that... that would seem like totally normal to me but to a guy that might feel like a bit of a... and I don’t really kind of know how to... it’s useful to know that! I’m not really sure of what the right solution is!” (Participant 8 para 58).

“Or... well, there’s stuff that I don’t really know whether it’s ok or not, like should... I offer to cook breakfast... you know, is that an ok thing to do or is this some sort of gender thing with that as well... I’m not really too sure...” (Participant 8 para 59).

4.3 Factors influencing the dating behaviour

Participants reported on their reasoning behind dating and the factors that influenced their decision. All eight participants shared their thoughts on dating. Their narratives on dating were divided into three sub-themes: reasons to date, reasons not to date and disclosing the diagnosis to partners/potential partners. The latter sub-theme has been incorporated as it appeared to form part of the thought process associated with participants’ decisions regarding whether to date or not. This theme and the sub-themes are depicted in Figure 4.

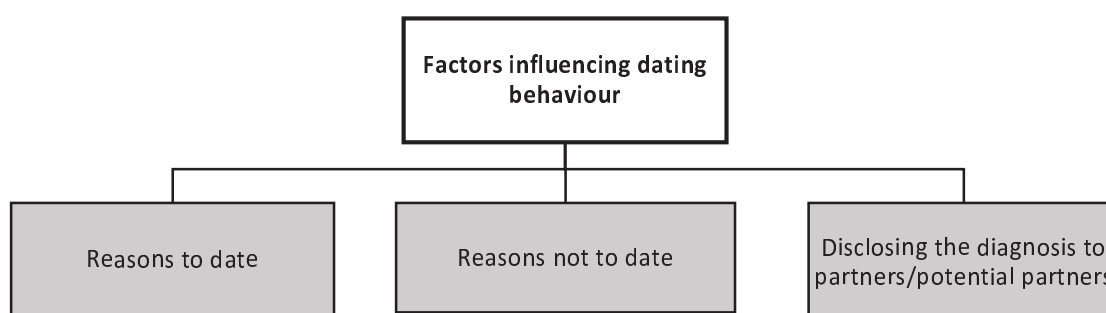


Figure 4: Factors influencing dating behaviour

4.3.1 “When are you getting married?” - Reasons for dating

There were several reasons provided by the 7 participants who reported their reasons for engaging in dating. Each of the reasons will be discussed below in order to illustrate them in more detail.

Four participants explained that finding someone interesting or attractive would be a reason to date them. This seemed to capture physical as well as intellectual attraction and a sense of shared interests:

“I guess also because we know a little bit about each other. Well, I certainly know a little about him because all of my friends – we have a mutual friend who is quite close to both of us so I kind of heard a lot about him. [I] kind of thought he was really interesting” (Participant 2 para 63).

“... [enjoys being] just being around their personality, I can find their personality really interesting, really funny, really sweet... it can make me think a lot about things in a good way rather than this sort of conflicting challenging way... and then there's the thing that sometimes they're just pretty to look at” (Participant 6 para 59).

One participant described how her past experience coloured the current choice of partner. She reported that she had married a partner hastily not only because they shared a similar background, but also because in comparison to her previous abusive partner, he was ‘amazing’:

“Yeah... the guy I met straight after that guy who was quite abusive and of whom I have just told you before, he was a student like me, same age as me, really nice guy, came from a similar background to me as far as I [me]... all that kind of stuff and I think because of how he just seemed to be just the opposite of the other guy [referring to an abusive partner] so then I kind of just thought: he's just the most amazing guy in the world and I it was just because I hadn't really... he was pretty normal and this other guy who was a ‘dick’ was kind of abnormal and this is kind of part of the reason that I thought I'm going to marry him” (Participant 8 para 18).

Six of the participants talked about wanting companionship as a reason for considering dating. Participant 4 who, for most part of the interview stated that she preferred to live by herself, remarked that despite the preference for living alone, she did feel lonely and that she would enjoy some aspects of a relationship at certain times:

“I would be less lonely in an empty flat and I would have someone look after me when I fall ill. So that will be nice” (Participant 4 para 50).

Four of the participants reported that they experienced a social expectation that they should be dating. Participant 2 talked about sensing a general social norm that people would find a partner and 'settle down' without naming a specific source of the social pressure. She appeared to suggest that having a partner, whilst under social pressure, was not necessarily in line with what she would choose in the absence of such pressure:

"Because I think it's hard to differentiate between your own wants and what you feel you are and social expectations of you... particularly social expectations..." (Participant 2 para 37). "... Oh, you grow up in an environment where, I mean my parents aren't like: 'when are you getting married?' Or anything like that. They are generally kind of... a general social thing is that it's the norm to settle down and have relationships, that sort of thing" (Participant 2 para 39).

Participant 8 described feeling some social pressure from her mother, although in hindsight, she recognised that it might not have been from her mother. Regardless of the source, she experienced pressure:

"Yes also kind of expectation. Like I didn't know why I felt this at the time but looking back I felt that my mother particularly, was very non-accepting of non-marriage relationships which I'm not sure how true that was, or how I got that impression because weirdly enough, like both my brothers had children with people they were not married to at the time. So I suppose there was a little bit of a sense that I was going to... accepted that I was going to live with someone and all that stuff that I would be expected to get married... which is kind of weird, now that I think about it. Because... certainly my mum had friends like, not close friends but people we knew of who were living with their partners but they were not married" (Participant 8 para 19).

Participant 4 even went so far as to fabricate a relationship in order to prevent other people from discovering that she in fact, did not have a partner. Her giggling while talking about this suggested that she was aware this could be perceived by others to be strange:

“But I didn’t want anyone to know [that she did not have a partner]. I pretended to have an imaginary boyfriend - and people would say: now why haven’t we met this man, and I would say he’s very busy [giggles] - but I invented him” (Participant 4 para 3).

Another reason for some participants dating was that they were ‘trying it out’ or experimenting with dating to better understand their ambivalence about relationships. It was as though they were thinking ‘why not’ rather than actively wanting to, or preferring not to date. This is illustrated by Participant 2 in the quotation below. She seemingly suggested some sense of pressure to justify her relationship or dating status. Participant 5 reported that she simply got married ultimately because her partner wanted to. She did not give any additional indication as to whether this was a mutual desire:

“I think that after some time you feel that you perhaps ought to because you can’t think of a significant excuse in the moment why you should not...” (Participant 2 para 119).

“...it’s really hard... I’ve never fallen in love... I don’t know what that feels like... I don’t... and again it was a logic based decision...” (Participant 5 para 46).

“... he wanted to get married, that was a big reason...” (Participant 5 para 50).

4.3.2 “Better off with a book...” - Reasons for not dating

Five participants reported a number of reasons for not engaging in dating. This covered a number of factors that they felt made it difficult for them to date - with some commonalities across participants.

Three participants reported experiencing some doubts regarding their ability to determine whether or not someone was interested in an intimate relationship with them. This led to feeling apprehensive about dating and is illustrated by Participant 2 in the quotation below. She reported that she relied on her peers to inform her of cues which she doubted she would naturally identify. As a possible consequence of the improved awareness of the difficulties associated with her diagnosis, this participant also seemed to suggest that her lack of experience might hinder successful dating:

“I will say to them [referring her friends]: Do you guys sometimes look at me and I don’t notice it? So they say ‘yeah!’ Although I can tell when somebody talks to me, to some extent. Although I am a bit slow on the uptake... like walking away I was thinking he was actually trying to chat me up, maybe... but in terms of physically, I think if somebody was eyeing me up, I would know... occasionally. It’s not the sort of thing I am good at... which I kind of contribute to... I kind of lack of experience so I think it affects me in that way... some missed opportunities I guess” (Participant 2 para 34).

Participant 6 explained that she was aware that there was a certain kind of interaction involved when dating or initiating dating. However, she experienced this as challenging:

“So there’s this whole thing of game playing, I think which is particularly hard where I think... I’m trying to figure out whether someone’s playing a game or if they are... because games are really normal in relationships and I think there’s... well, this is my impression any way – like people say: oh, I don’t play games – but everyone does... even like moderating how interested you appear in the other person... it quite hard to figure out really...” (Participant 6 para 62).

Participant 2 described having difficulties in determining whether someone wanted to be friends or to be in an intimate relationship with her, while Participant 8 could not figure out whether a potential partner was ‘playing a game’ with her or not. It was apparent that neither of these participants seemed to have developed an effective strategy for supporting them in negotiating the type of situations described:

“I think certainly when I was a teenager, early 20’s, I had trouble working out whether someone was being friendly or romantically interested. And that I think is why I probably spent six months going on one year moping over this one guy who was interested in being friends with me but not in a romantic relationship” (Participant 2 para 115). “Or maybe it’s the kind of borderline flirting which is sort of... they wave the cheque but don’t want to cash it! You know, so when working it out, people flirt for the sake of it rather than as a kind of pre cursor - and to see the sincere intention is kind of difficult for me” (Participant 2 para 124).

“... I’m trying to figure out whether someone’s playing a game or if they are... for example you might think about them twenty times a day but you don’t tell them that - do you know what I mean? But for me... I have kind of learnt that’s not sort of necessarily instantly obvious to me what you would tell somebody or what you wouldn’t” (Participant 8 para 68).

Another barrier to dating that emerged from two interviews, was that dating was considered a lot of effort. This is illustrated in the following quotation from Participant 5 who seemingly suggested that she would rather occupy herself with something that did not require quite so much effort. More specifically, Participant 5 described dating as a type of game of which she did not understand the rules. This appeared to have made her fearful of dating and led to her avoiding dating ‘at all costs’:

“Yeah... I just didn’t get involved... cannot understand it - it’s like a ritual I do not understand... don’t get the ground rules... don’t know how it works... therefore cannot play along - and my way of handling it was to utterly focus on study so I didn’t have to go out to pubs and clubs and places with that – and avoided it at all costs and didn’t have to play along” (Participant 5 para 6). “... I don’t know... to me it looks like an awful lot of hard work and hassle to figure it out... I could probably be better off with a book!” (Participant 5, para 94).

Not understanding the nature of dating was echoed by Participant 7 who provided an analogy for the confusion she experienced, and therefore her reason for avoiding dating:

“... It’s like watching a TV show and having the soundtrack of something else. It’s meant to be this one thing, I’ve put this thing on specifically because I want to watch this thing but I’m getting a soundtrack of something else...” (Participant 7 para 34).

One participant reported that she simply felt she was too busy to have time for dating and therefore, did not date. She appeared to suggest that her schedule was related to ASD and associated difficulties, in that she felt compelled to complete arguably unnecessarily prioritised tasks:

“And I guess I don’t prioritise relationships over my busy Autistic schedule” (Participant 4 para 11).

“I’m busy now... I couldn’t see them [potential partners] on the weekends because I’m very busy. For example, I spent the whole Sunday writing out my 2014 diary... that took a whole day to do!” (Participant 4 para 21).

This participant also highlighted that she preferred to spend time by herself:

“... I’m too busy for other people, I don’t like going out all the time at night like other people do - I didn’t go a night club until my late 20’s although I know 50 year olds who are still clubbing. I just... I like my own company... and I think my best friend is me...” (Participant 4 para 20).

4.3.3 “Warts and all...” - Disclosing the diagnosis to potential partners

Seven participants discussed their experiences of disclosing their diagnoses to partners or potential partners. This theme is sub-divided as follows: reasons for disclosing the diagnosis, concerns about disclosing the diagnosis and experience of actual disclosure.

4.3.3.1 Reasons for disclosing the diagnosis

One of the main reasons given for deciding to disclose their diagnoses involved supporting others to understand and accept some of the difficulties which the participants faced. The participants quoted below seemed to feel that an improved understanding or insight into the cause of their difficulties could help a partner or potential partner to accept and or better understand them:

“It [disclosing the diagnosis] gives a reason for why: why are you the way you are. So it helps them to understand you. If they are going to walk out on you because of your Asperger’s, they are not worth having in anyway. Warts and all” (Participant 1 para 26).

“... I found that the more successful relationships haven’t been ones that dodge that topic but actively... you know... accept that this is occasionally what is going to happen and sort of make jokes about it but in a positive sense not in ‘ah you’re a freak’ sense but in a ‘ah you’ve gone and done that again’, ‘you gonna confuse them’ kind of sense. Um... and that way in-jokes... and I do love in-jokes” (Participant 6 para 59).

Four of the participants described feeling obligated to disclose their diagnosis to others. They seemed to suggest that not disclosing the diagnosis would be unfair and that they would find it difficult to be in a relationship where they had not told their partner. This appeared to reflect a value judgement suggesting a belief that transparency is an important quality in a relationship:

“... I’ll immediately confess to things... not to be accused of things but for example, I would... I probably feel I did not need to tell him but I ought to tell him” (Participant 2 para 75). ”

“Keeping something from somebody I feel is very difficult to do” (Participant 2 para 79).

“Because I don't think it's fair to them to have them entering a relationship thinking that this relationship is going to be with someone who is just quirky who does these things because they choose to. When you told someone it's Asperger's or it's autism, it's kind of unwritten that these things can't be controlled and [you] don't choose to do these things” (Participant 7 para 64).

Furthermore, Participant 7 simply found it would be impossible to hide her ASD in an intimate relationship:

“It's part of me! It's like trying to hide my leg. It's not gonna happen” (Participant 7 para 66).

Five participants said that they felt that in disclosing their diagnosis they could be reassured that their relationship might have a better chance of success in the longer term because their partners would be more understanding of them and the associated difficulties they faced:

“...because in my mind if they honestly care about you, it won't matter. They will try to find out more. They'll find out how they could help... they might be the sort of person who, when reacting bad in public, might say... help you” (Participant 1 para 24).

“The whole point of a relationship is warts and all. If you can treat the warts - great, but if not, you take the person with them. And I have them” (Participant 1 para 27).

“I suppose it is like buying a house or a car – you want to know what the problems are with it before you choose to make a decision about it rather than discovering something later along the line” (Participant 2 para 72).

Similarly, Participant 8 explained that her disclosing the diagnosis at the beginning of a relationship provided not only a reason for her difficulties, but also pre-empted her difficulties to the her potential partner:

“... because I wanted them to know that things might be a bit different from what they might be used to... to provide a reason, I think... and to sort of, I guess so that they wouldn't sort feel like... I guess, yeah... pre-empted actually. I guess I wanted to be rejected at that point – if it was that I was going to be rejected for this...” (Participant 8 para 34).

“I guess once you get into a relationship with someone you're kind of willing to deal with a difference in... you're kind of already got established in this thing and it's a lot harder to...” (Participant 8 para 35).

“So yeah, if the rejection is going to take place I'd want it to be sooner rather than later” (Participant 8 para 36).

4.3.3.2 Concerns about disclosing the diagnosis

Five of the participants raised concerns relating to the disclosure of their diagnosis and associated behaviour. For example, Participant 2 disclosed that she had concerns about disclosing the way in which she coped with some difficulties and whether a potential partner would find this unattractive:

“Actually I don't tell him everything because some stuff I do... I find embarrassing. For say example, if I got really stressed about something and was trying to throw myself against the ground to get some sort of sensory feel, some kind of pressure, or kind of impact that would calm me. Or kind of my parents need to hold me, not to restrain me because I am kicking off, but would hold me very tightly to feel calm. And I did not say all that because it would sound possibly scary or unattractive...” (Participant 2 para 84).

Four participants spoke more generally about concerns that they had regarding the way in which they might be judged by potential partners should they find out about their diagnoses. This was illustrated by Participant 3 who appeared to believe that there was a negative stigma associated with having ASD:

“A little bit scared. Because people don’t... like if you say - oh, I have Asperger’s - they say – what’s that - and I say - well, it’s like a form of Autism - and I think Autism still has this really big stigma so that if I tell someone that - I’m Autistic - or like - I’m high functioning like Autistic - they like just think of someone who can’t communicate... yeah, I think that’s like a really bad portrayal” (Participant 3 para 26). I was kind of worried that he wouldn’t understand what it was or he’d think I was just this kind of person who would just sit in the corner and like rock because I wouldn’t communicate and this was like no, it’s really not like that” (Participant 3 para 27).

Participant 8 explained that she was apprehensive about disclosing her diagnosis to potential partners as they might shy away from her and the prospect of establishing a long term relationship, and the possibility of having children together due to the genetic risk involved. On the other hand, she did disclose the diagnosis with the aim to weed out those who would have such an approach.

“They might do... because I guess you kind of see it through a disability kind of lens and people think: maybe if I was to have children with this person, would they also have Asperger’s Syndrome and I think it’s that kind of thing that can go on in people’s heads. You then don’t get a chance for them to sort of know you because of that but yeah, I guess that’s why I want it to be out there...” (Participant 8 para 39).

4.3.3.3 Experience of actual disclosure

Some participants described their experience of actually disclosing their diagnosis of ASD within intimate relationships. Three participants reported a positive reaction from their partner. Participant 3 described her partner responding with an assertion of acceptance:

“Yeah, that was one of the first things I said, oh yeah... uhm... he was like okay... that’s fine... that’s not a problem... that’s like part of you and I like all of you, so... I like that too...”
(Participant 3 para 25).

Whilst three participants described a positive response from their partners, three others experienced their partners as disappointed. Participant 5 seemed to sense that her partner’s disappointment related to the realisation that she was unlikely to change no matter how much effort either of them made:

“...he was disappointed... (Participant 5 para 94)... I think he was really disappointed because I think for years he thought if I work hard enough on this girl, I’ll get her to change and then he realised that wasn’t ever going to happen” (Participant 5 para 21).

Participant 7 described her experience of a partner no longer being attracted to her when she disclosed the diagnosis. This seemed to relate to the stigma of the label ASD rather than to her difficulties, which she suggested he previously viewed as ‘quirky’ and did not seem to mind:

“...and then I told him. And it was... I could see that wall come down. It was like I was now off limits... it was like, it was like I suddenly told him I had the plague. It was like, ok, you’re cool to talk to and everything but no...” (Participant 7 para 51).

“If he’d have reacted differently to me telling him. It was like having a name to put to all these quirks that I have. It wasn’t an ok thing. It was an ok thing to maybe consider dating the quirky girl but dating an autistic girl is not ok” (Participant 7 para 53).

Four participants elaborated on the responses that they had received by talking about how both parties attempted to accommodate each other’s needs and perceptions. For example, Participant 3 described how her partner supported her in managing social situations where she was uncomfortable or struggling:

“That he knows me. That yeah, he knows me and knows like the weird stuff that I do and he’s still okay with that - he doesn’t run a mile - and he knows like how to calm me down when I’m having a panic attack. He knows exactly what to do and he knows like if other

people are saying like inappropriate things, he can tell if I'm uncomfortable and he'll like take me out of that situation" (Participant 3 para 20).

Participant 5 explained how she found it difficult that her partner only made efforts to accept and accommodate her needs after she had been diagnosed with ASD. She appeared to suggest that prior to the diagnosis, he was not willing to adapt to accommodate her needs but this changed when he had a diagnostic explanation for them:

"I've been telling you this for years and now a book has said it... because there's a label on it, now you'll do it while I've been begging you to do this for years – so it's enough cause to get me upset about it..." (Participant 5 para 24).

She went on to explain that the process of being accommodating was mutual and that she also had to adapt her behaviour in order to maintain her relationship. She explained that whilst she recognised the importance of compromise, she found it tiring:

"I think it [playing along] can be quite exhausting, but sometimes you have to do it, don't you?" (Participant 5 para 40).

Participant 6 described her experience of actually disclosing the diagnosis to her boyfriend. She seemed to suggest that her partner's views and subsequent reaction were influenced by depictions of crime in the popular media. Consequently, she felt disappointed by his reaction:

"He said he wasn't sure at first because he... he'd heard all these things about Autism, which... I mean he's in the States and in the States, it's even worse than it is here like whenever there's a shooting in the States and it's not a black guy or a Spanish guy or an Arabic guy doing it because in those cases it's crime or terrorism or whatever. Cause a white guy doing the shooting, then immediately, people will go 'oh, it's Autism!" (Participant 6 para 25).

"... and that's saturating the American media so when you're... when I say I'm on the spectrum, people immediately jump to those things and imagine me as this sort of weird creepy loner sitting in their room, sort of thinking about how to construct a tank the size of Belgium or something just... completely wild and bizarre and people really jump at these

things so... when I say that, I can understand a bit why he'd go 'uhm ok, I'll think about this a bit' but...[I felt] a little bit disappointing but not ... I could understand why he was doing it because he... didn't necessarily know any other people who were on the spectrum so I can understand why the media has a tendency to distort things quite a bit” (Participant 6 para 26).

Participant 6 also explained that once her partner had a better understanding of the disorder, she experienced disclosure affirming:

“Affirming I guess. Just the idea that I don't have to hide it or I don't have to... cover for it is really helpful as well” (Participant 6 para 28).

4.4 Sex and sexual experiences

Although they reported it in different ways, all eight participants spoke about sex. The sub-themes within this overall theme include: sexuality, difficulties related to sex and negative sexual experiences. The theme and sub-themes are depicted in Figure 5.

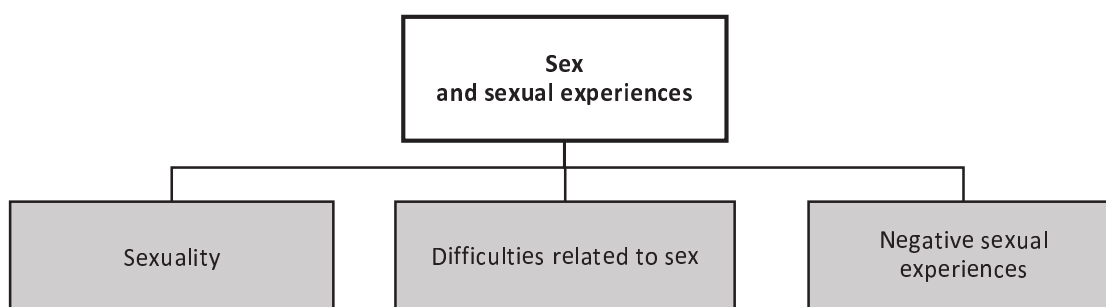


Figure 5: Sex and sexual experiences

4.4.1 “...no such thing as a platonic relationship in this country ...” -Sexuality

All eight participants spoke about their sexuality - those who engaged in sexual behaviour as well as those who expressed a-sexuality. One participant described herself as being a-sexual and stated that she had never experienced sexual feelings. When asked to define the specific nature of

relationships, which interested her, she reported that she was interested in platonic relationships only:

“... I was born without sexual feelings... it’s not uncommon: a lot of people with Autism do have sexual feelings but some people with Autism were born without them... so I’ve been asexual all my life... which means I am not interested in men or women” (Participant 4 para 3). “But when people are like... in just pairs... it doesn’t... it is not normally good, but I just don’t normally show an interest in that side of things - I just want to be looked after” (Participant 4 para 5).

Another participant placed herself on the continuum of a-sexuality and referred to herself as ‘demi-sexual’. To her this meant that she was not attracted to many people:

“I see I suppose, what is a kind defining feature of what’s going on for me sexuality wise – is not being attracted to very many people which is generally referred to as demi-sexuality or grey sexuality as a ... on the a-sexuality scale and more and more I’m kind of thinking it’s more a sexual orientation” (Participant 8 para 1).

Later on in the interview Participant 8 explained that despite considering herself ‘demi-sexual’, sex was important to her:

“...boyfriend I suppose, that kind of thing, the sexual element of that relationship would be quite important to me” (Participant 8 para 72).

A-sexuality affected relationships differently. For one participant it led to her not engaging in relationships as she believed that sex is an inevitable element and also inevitably expected in an intimate relationship:

“And also, men want a sexual relationship, they want to get inside your knickers - there’s actually no such thing a platonic relationship in this country. I mean, if a man moves in with you, he wants to get inside your knickers, you know” (Participant 4 para 18).

“Nobody’s going to have a non-sexual relationship - everyone has sexual feelings... I’m in the minority” (Participant 4, Para 19).

While another participant was still engaged in relationships, her identification with a-sexuality seemed to impact negatively on the sustainability of the relationship. This led to her feeling uneasy about being 'demi-sexual' and she would have preferred it to be different:

"I wouldn't choose it. It's got some really negative, really difficult things around it... like... I have a therapist and we sort of talked about this... as soon as a partner knows this about you, it's very difficult for them not to take you completely for granted because for them..." (Participant 8 para 5).

Other participants spoke about their sexuality and sexual activity being an important part in their relationships. However, they differed in their preference for sex within a relationship or out of a relationship. Three participants reported that they preferred to be in a relationship with someone before engaging in sexual activity, illustrated by the quotation from Participant 2 below. She appears to have a sense that sex would not be meaningful if it took place outside of an intimate relationship:

"It's very difficult because I don't think there is a clear definition of them at all. For example, I wouldn't say it's just about sexual desire... because romance can be separated from sexual desire. But then some people can separate it and some people can't..." (Participant 2 para 133).

"... I think, go through the motions where you feel soulless and horrible, but I suspect I probably could, but I wouldn't want to because I think if I feel anything, I would feel completely mechanistic and I wouldn't want that - it would be a kind of half way thing - because I do think some people could go out and get off with somebody without feeling any romantic involvement but still feel having got some pleasure or enjoyment out of it, or some kind of buzz from it. I don't think I really could... I probably could but not feel anything at all... but then I think I could do this with as much enthusiasm as... cleaning my teeth!" (Participant 2 para 135).

When talking about sex, Participant 7 presented a contrasting view to most of the other participants as she preferred to only have sex with those she did not feel an emotional connection with. She believed that this related to her difficulty in establishing and maintaining effective intimate relationships, and connecting with others on an emotional level:

“Because, people come with all these emotions and complications and... this is going to sound really bad but I know for everyone else, it's really weird but it works for me. I don't date. I have one-night stands. I tried dating and it just, it didn't work” (Participant 7 para 2).

Participant 5 revealed a similar experience. Although she did not speak about herself directly, she did state that the absence of a relationship would not hinder her from having sex:

“You know, I think the lack of emotional connection... I and I bet lots of women with Asperger's could be sexually promiscuous in... I reckon... and this is speculative, don't know... reckon they could probably not have go through any of the emotional wrangling to be able to sleep with somebody and then done... I'll get on with work the next day...” (Participant 5 para 88).

4.4.2 “The map is a lot less clear...” - Difficulties relating to sex

Some participants talked about some of the difficulties that they had encountered when considering sex within their intimate relationships. Participant 6 described how awkward it could be when initially having sex with a partner:

“Yeah that... that can... that can that can be quite awkward, sort of a case of ... um... the sort of need of aw... awkward clarification... in advance... and it's a lot of trial and error as well, which can mean that the first time or the first few times, it can be really... almost like um... watching an embarrassing comedy... this sort of 'oh god, this is going horribly wrong, I just want to walk out now'...” (Participant 6 para 61).

“Yeah, entirely, it's um... yeah it makes things... it avoids ... that sort of wo wo screeching of the brake sound effects where you're suddenly thrown out of the moment and thrown into a sort of almost conflict state...” (Participant 6 para 63).

She also said that it could be a further challenge to learn how to behave during sexual interactions as this was not something one can generally or naturally observe from others with the aim to learn from peers:

“... again going back to the sex room... encounters and stuff, that can be quite awkward because... if you're sitting down having a talk with someone in a coffee shop then sure, you've done that loads of times, you're used to that and you know you're... you see a lot of people doing that as well - fine, ok, you've got that one down but when it comes to sex? The map is a lot less clear....” (Participant 6 para 67).

Participant 8 mentioned her worry that her partners might think she is 'weird' during sexual intercourse when she needs to take steps to accommodate her sensory difficulties. However, she thought it was possible for a partner to perceive her actions as 'rejection' and this could consequently impinge upon their relationship:

“Like the sensory sensitivity kind of things... skin against skin contact could be quite unpleasant and trying to have sex with bits of clothing still on... sometimes trying to put a sheet or pillow between me and the other person... just kind of try and sneak things like that... because I sort start off with: this person's going to be feeling the same thing as I'm feeling so that kind of sensation of rubbing together would be as annoying to them as it is to me and then I put the sheet... and then they're going to feel like: why did you just do that... do you not like me... it's like don't you want to be doing this... it's this sort of interpretation...” (Participant 8 para 28).

“Yeah, yeah, yeah... and it gets kind of interpreted as a sort of rejection... or just I think probably what bothered me a bit more was the idea that they thought that I was weird...” (Participant 8 para 29).

Participant 5 reported that she and her partner had different ways of approaching sex and that she struggled to understand his approach in these circumstances:

“We'd sort of do this, spend ages just touching one another and enjoying the atmosphere and... well, I don't see the point in wasting loads of time doing that. Basically, I see it in a terribly functional way... and exactly the same way as when I left university, a friend of mine said: let's go travelling... we can take in San Francisco, we can take in... she used this term 'take in'... just kind of being in the environment and absorbing – and in a sexual sense, I see it very much in the same way. I was like wondering why 'take in' San Francisco: are we going

to do something there... I'll go there if I've got something to do there... work... but it's pointless to go there just to 'take in'. And if I'm really honest, I see sex in exactly the same way!" (Participant 5 para 77).

Similarly, Participant 3 described her struggle with the idea of flirting and the communication between individuals in the build-up to a sexual experience between them:

"...it's like kind of the mind games around that, that's the problem... it's not the act itself - it's the situation!" (Participant 3 para 60).

"Confused. Like yeah... that's always been a bit confusing... it was quite difficult to gauge" (Participant 3 para 61).

4.4.3 "I felt like I was a cream cake he was looking at..." - Negative sexual experiences

When discussing their sexual history, four participants mentioned negative historical experiences. These broadly captured two types of experiences: coercion into sexual activity, and unwanted sensory stimulation. Some participants talked about how they had been sexually taken advantage of or exploited in the past:

"... and he was there for me as a friend and looking back, I can see that he did take advantage of me because I was kind of vulnerable and upset and he was like - no, all was going to be all right. We started like a relationship but I didn't really like him like that but I felt that I couldn't say that because he had been so nice to me. So the sex was absolutely horrible and felt uncomfortable" (Participant 3 para 64).

"[I was] worried to begin with, to like go into a relationship. I didn't like want the same things to happen, but like, yeah... he wasn't the same as the rest of them... like he wouldn't like force me to, not like force but coerce me to do anything I didn't want to do" (Participant 3 para 71).

"... he was able to manipulate me, and I'm not sure whether this was intentional or not, but any sort of suggestion that I was not... if I didn't want to do something sexually... the kind of

indication that I was not very grown up, was actually very powerful and kind of made me do things that I wouldn't otherwise have done. And when I look back on that, it was a massively, incredibly exploitative... an exploitive situation... but in a sense I kind of... I feel like it was kind of inevitable because of my where my head was at..." (Participant 8 para 10).

One participant described feeling objectified by a past encounter and that she did not know how to respond to this feeling:

"He was treating me like some kind of possession or something! I was mad at him. I felt like I was a cream cake he was looking at – drooling. Very off-putting" (Participant 1 para 40).

"I got quite angry. I didn't like it. It gave me the creeps. Felt like I was an object, not a person..." (Participant 1 para 41).

"I didn't know how to respond so I just kept my mouth shut" (Participant 1 para 42).

Participant 5 explained that she did not like to be touched in a sexual manner although she did allow this to happen anyway and tried not to show her true feelings. She implied that she felt she 'had' to succumb do this without naming an overt source of pressure:

"I don't like people touching me very much... there again... I just have to wear a mask..." (Participant 5 para 85).

4.5 Experience of relationships as a person with ASD

This theme aims to capture the participants' experiences of being in relationships and how they perceived this as being linked to ASD. This theme has three sub-themes which include: challenges experienced in relationships, aspects of relationships they enjoyed and concerns they had regarding the natural progression of relationships. This theme and the sub-themes are depicted in Figure 6.

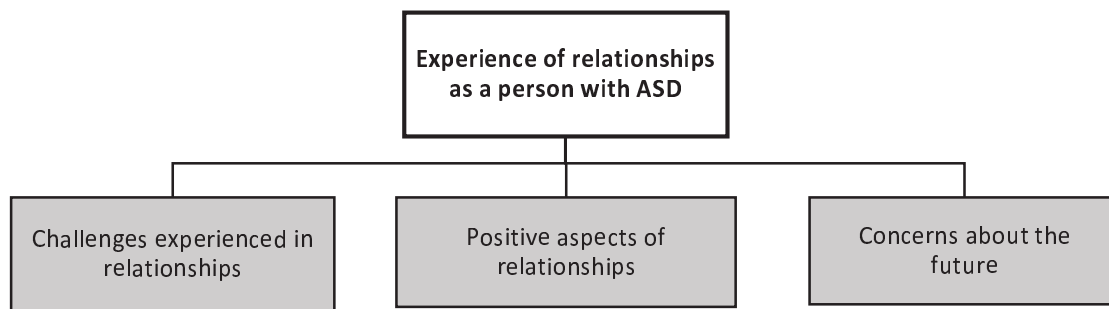


Figure 6: Experience of relationships as a person with ASD

4.5.1 “I like to see them as requests but people see them as rules...” – Challenges experienced in relationships

All eight participants spoke about difficulties which they experienced in their intimate relationships. These eight participants between them covered a wide range of difficulties, which are noted under the following sub-themes: difficulty in understanding partners, managing the spontaneous nature of relationships and managing own interests.

4.5.1.1 Difficulty in understanding partners

One of the pertinent difficulties that the participants and their partners shared was related to the incompatible ways of expressing care towards one another. This held implications for the sustainability of their relationships. Participant 3 explained that she and her partner also had different ways of consoling each other and that this had resulted in her behaviour being misinterpreted by her partner as rejection:

“... [referring to the difficulties in relationships] like learning that I don’t want to hug all the time... yeah... it definitely was tricky because he would get really upset that, like... just normally day-to-day... I was ok with just hugging, like holding hands and everything like that. But if I was particularly upset, I just kind of wanted my own space and because I was upset, he would want to hug me and like try to make me feel better but that would make me feel worse. And it was kind of trying to get him to understand that it’s not that I don’t want to

hug him, I just don't want to hug anyone. I need my own space, just to kind of let my brain catch up to everything and kind of process whatever it was that upset me on my own... and that really hurt his feelings to begin with" (Participant 3 para 6).

In this instance Participant 5 explained how she found it difficult to understand why her partner bought her gifts she could not use. She found the nature of gift giving and the associated dynamics a challenge to deal with. However, she also considered herself to be in the wrong for feeling this way:

"And it's very difficult because my husband's mode of showing love is to give gifts and I've shut that down in him because I've said: please don't give me stuff, just don't... because it's more hassle than it's worth..." (Participant 5 para 38). "I was aware that gifts used to irritate me and I used to think: what's wrong with you, woman? ... I knew I was the wrong one, yeah... but I couldn't work out why it annoyed me so much!" (Participant 5 para 36).

Two participants reported having communication difficulties. They highlighted their tendency to take things literally, rather than trying to attribute meaning given the current context. This impacted upon their relationships. Again, Participant 5 described becoming pre-occupied by the literal meaning of words used, rather than the implied message that her partner may have been trying to communicate:

"I get very hung up on the words he uses and I'll become quite sort of militant about that, and sometimes miss the meaning because of his mode of communication... Yeah, and I get quite hooked on these. So he might say to me: your manner of speaking is quite aggressive – and I'll be like aggressive... It's not his fault that he has only got one word for... he used the word 'aggressive' to mean bad, he'd use it to mean 'grumpy', he'd use it to mean 'over excitable'..." (Participant 5 para 70).

Another difficulty, related to focusing only on what was actually said rather than what was implied, was that Participant 5 did not pick up on 'hints' that her husband provided. She was able to appreciate that this might be confusing for her husband:

"This is what he was trying to do, yeah. So if he was planning something or had an idea, he would kind of hint... have you ever considered... imagine he wants to go the theatre in London which is big deal for me. He might say: oh, what would like to do for your birthday –

to get me kind of used to the idea of birthdays... celebration. Then the following week he would say – have you ever been to a West-End musical? I would then talk about those I've seen, I'd just give him the facts. I wouldn't think: is he leading to something. And then it would come as an utter surprise to me... sheer shock when he thinks he's prepped me for it! And suddenly the tickets arrive and I freak out because I've got to go to London. It's very confusing for him, I think..." (Participant 5 para 13).

Participant 2 shared her difficulties with understanding, in the moment, that others might not be holding the same representation of a situation as she did. She found this to be an obstacle for interpersonal effectiveness in intimate relationships. She was able to recognise that, for her, there was a difficulty between having knowledge about an interpersonal process, and being able to effectively implement this knowledge in the context of a relationship:

"But I suppose not being able to work out if somebody else might be reading the situation different to you, is something I could think about quite theoretically now. So I can say to you yes, even I think this is going on but that does not necessarily mean that they have the same interpretation of the same situation that I do. But I think actually in that situation I would find it very hard to have the kind of theory of mind to have that awareness" (Participant 2 para 121).

Another difficulty addressed by three participants as having an impact on intimate relationships, was being mindful that their partners might not share their interests and have been depicted in the descriptions provided by the participants below. Both participants seemed to suggest a sense that they potentially had little control over the direction of their attention at any given time. This was especially challenging when coupled with an awareness that their partners could find this difficult, particularly when they (the partners) expected to be the focus of attention:

"So like the biggest kind of thing that would affect our relationship in the beginning is that if he was talking to me and I saw a dog, I would like completely black him out and just be all consumed by the dog and I would be like 'look at that' and blank him and go and talk to the dog. I'm much better now and I have dogs personally so it's not so bad... but he used to really get upset because I'd stop listening to him and stop interacting with him and just be focussed on the dog..." (Participant 3 para 4).

“.... I like just see a cute dog and I would be like - ah, look at that dog! It’s so cute, it’s wagging its tail - or something like this, that or the other and he would get like - for god’s sake Linda, I’m trying to talk to you here - and I was like - sorry, what were you saying - and he’s like - uhg, it doesn’t matter now...” (Participant 3 para 5).

“All kinds of things. Like they might find that my whimsy or tendency to you know, saying that I’ve lost the whole evening because I wanted to read about the geography of Iraq on Wikipedia or I decided spontaneously to watch every episode of South Park from season 7 or whatever. Uhm... they are lots of quite shallow examples but they are the ones that can easiest to mind...” (Participant 6 para 18).

4.5.1.2 Managing the spontaneous nature of a relationship

Five participants highlighted being aware they had a need for clear rules and consistency in their lives, and talked about how this created difficulties in relationships where they held an expectation that others follow/fit in with these rules. Participant 4 described some of her ‘rules’ and her appreciation that others might find this ‘demanding’. She seemed to feel that this could hinder a potentially rewarding relationship should a partner spend more time in her environment:

“I’ve got certain routines...” (Participant 4 para 59). “... now if you don’t mind, I’ll go through a few, like shut the lid before you flush the chain, remain seated during the entire performance... which soap to use, which towel to dry your hands on! And people get fed up with my rules... if you’re coming around a few times in your life, that’s okay but if you were coming around once a week, it will drive you potty (pardon the pun!)” (Participant 4 para 60).

“I like to see them as requests but people see them as rules and see me as very demanding” (Participant 4 para 61).

Participant 2 described that the need for structure and routine extended, at times, to less tangible areas such as conversations with others:

“We talked about things we have in common, common interests... it’s easier for me to talk about things rather than just kind of... I don’t know... chat” (Participant 2 para 61).

Four participants found it difficult that not all intimate or dating relationships follow a similar pattern or set of rules. The participants quoted below appeared to suggest that they experienced some level of anxiety as a result of the lack of rigid structure and rules for dating relationships:

“I accept that it is. In some ways I feel I need guidelines on how I go about conducting a relationship with somebody...” (Participant 2 para 143).

“...that supposition right from the start and because I don't really know much about them, I'm feeling like I'm having to, I'm having to conform to a test where I don't know the questions...” (Participant 6 para 16).

“It's just, I work differently and there's nothing wrong with it, it's just different. But dating, you have to kind of... to me it means being very rigid... and in dating you kind of have to have a certain amount of flexibility. I don't do change at all! It's just no. It doesn't work, it's like it should be a, b, c, d. If you go from a to d and miss out b and c, my brain shuts down. And when you're in relationship, it's... often times it's unpredictable and it doesn't follow rulebook and ... there is no pattern, there is no continuity and it's just... no...” (Participant 7 para 37).

The nature of this difficulty was captured by Participant 8 when she questioned the practical everyday implications of being in a relationship:

“Like what do couples do together... like how do they spend time together, what sort of things should you talk about and not talk about... what... how do you kind of know what someone's feeling and how should you respond to that... and then I suppose like the kind of questions on top of that tend to... like how do you respond to things... like things... the love kind of... like... the real popular cycle... like how do you kind of have good relationship type of things... how you could be in a relationship that would keep together, I suppose that kind of... that's advanced for me...” (Participant 8 para 57).

Four participants talked about how they would have found it easier if there were prescribed rules for their relationships:

“How do you find your way to a stable long term relationship when you don't have a rulebook?” (Participant 6 para 72).

“...there isn't much in terms of manuals out there, is there? I mean like if something is written for aliens... sort of like how to pass yourself off as a human – that would be really cool, that's what I would like as a starting point because then I could kind of deviate from that as I choose” (Participant 8 para 56).

Participant 8 also said that it was harder to learn about intimate relationship behaviours through observation, as she might learn other social behaviours. She seemed to relate this to not generally being able to observe the more intimate aspects of other people's relationships:

“Frankly, I don't really know how they see it. I would just love to have a video camera going to see what other people's relationships are like. And I mean, not that they should be normal, but you know, just so that I could have a sense of: ah, you can do it that way or that's what people expect...” (Participant 8 para 54).

Participant 2 spoke about how she might manage intimate relationships given the absence of tangible guidance to relationships:

“But I think it is that because there is a desire for a kind of certainty or a pattern of how you are meant to carry on - a sort of protocol about romantic relationships with people...” (Participant 2 para 155).

“... I haven't talked about it with my friends... actually I have, a little bit by watching... with my closest friend who's in a relationship for seven years... I guess she's in a much more established relationship - and I kind of saw what they did... a little bit... being an observer in a way. I think when I think about it, it feels I was in the wardrobe, peeping out!” (Participant 2 para 157).

Participant 7 talked about how she developed some of her thoughts about relationships based on observing her mother; perhaps the one instance where insight could be gained due to the close proximity of these relationships during childhood:

“Coward. Coward. My mother is one of those women that can't function unless she's in a relationship. And there are four of us, there's me, my brother, my sister, my brother, we all have different fathers. She's been married twice. She's now with another guy. And over and over and over again, it gets complicated and it gets murky and she gets wound up. And everything gets tense and overwhelming and... boom he's gone. I've never seen a marriage that has lasted. I've never known... you see them in restaurants, these couples who have been together for twenty years, they don't talk at all! They don't even say 'pass the salt'! It's like they've run out of things to say...” (Participant 7 para 32).

Related to the above, Participant 3 reported that she found it difficult to understand how despite her doing 'everything she should' and following the perceived required steps to engage in a relationship, her partner still was not interested. This seemed to reflect her feeling that there should be a set structure or predictable pattern to relationships in such instances. It is perhaps also important to note that the participant reflected on the situation after the moment had passed and then assessed the situation in a different way:

“I was like hang on a minute, I'm doing everything I'm meant to be doing - like you see in the movies... like you buy flowers, you surprise them like - hey, I've got dinner!” (Participant 3 para 35).

“.... looking back, she [her partner] kind of needed her own space and I didn't respect that... but at the time I couldn't see it... I just kind of thought that when people were upset, they want to be enveloped... that's what everyone wants. It didn't occur to me to think that when I'm upset, I just want my own space...” (Participant 3 para 49).

More generally, having difficulties with social interactions and the effort it took to engage in a socially effective manner was highlighted as a factor that impacted on participants' relationships. Two participants talked about a need for respite after interaction due to the strain of needing to consistently and actively assess interactions whilst engaging in social activities. Participants 2 and 8 specifically mentioned that it took a lot of effort to maintain an effective relationship or even a single interaction, and said that after interaction they needed to be alone. Participant 2 possibly suggested that this need for rest or to be left alone, would make it difficult to maintain an intimate relationship:

"I find the social interaction tiring. One-on-one is not quite so bad, but I rest afterwards..." (Participant 2 para 98). "... really resting, yes. But also going on the computer and really not talking to people for a couple of hours. Sometimes actually, yes it could be that I go to bed" (Participant 2 para 102).

"... I think about that [need for rest] and relationships and you know, like the word 'autism' and it means 'self-focussed', doesn't it? And I've kind been thinking about how that works and my everyday life, like last night I was in the kitchen and [my house mate] had just got back with some crockery and stuff and putting it away... and we were chatting away there and what I actually needed to do right there was to make my dinner. But because we were chatting away, and I really enjoy talking to her and she's great... but because I had been talking to her for about twenty minutes, I needed to go upstairs and just be by myself for like ten minutes and that's the only reason that I... you know, there wasn't any particular reason for it... it was just... and I almost felt an addictive feeling like when you really want a cigarette or a cup of coffee... that was what it felt like... oh, I have to go upstairs and just be by myself for ten minutes. And I had been alone like for most of rest of the day and I just even don't understand what that's all about and it's... I feel that quite strong need to be quite a lot but..." (Participant 8 para 68).

"... yeah... I mean... yeah... there's a sort of weird kind of a thing that goes on where like that self-focus and the loneliness are almost kind of part of the same thing... why have this incredibly strong almost addictive like drive to be by myself, and yet feel this like enormously crushing loneliness at the same time... I just don't understand how they kind of can be reconciled... it's kind of being pulled into two directions at once..." (Participant 8 para 69).

4.5.1.3 Difficulty in managing conflict

From the above sub-themes one could infer that participants had difficulty in managing conflict, however, only one participant spoke about the difficulty she had due to her and her partner managing conflict in different ways:

"He related in an emotional way and I reacted in a practical way. His emotional reaction was: right, I'm upset with you, so I'm going to be hurtful. And in my Asperger's way, I asked: why would you be doing that? And I don't... one thing I didn't know - people did lash out in anger

and say things they don't mean – which apparently people do, but I don't do that. And so the damage that has been done because he was so hurt... some of the things he did and said which I now memorise like a tape recorder... down to the date, replay it. So it's stuck, it's indelible now. He says he's got it off his chest because that's what neuro-typical people do... and this friend around the corner here says: but that's what people do... they kind of splint off something they don't mean, just to kind of bat off away hurt... and I'm like: why would someone do that?" (Participant 5 para 110).

"And when I do say things to him that I mean, he's like: you can't possible mean that! I'm not taking that on board so I say: no, I do mean that... I know you're saying that because you're upset but I actually do mean that... I'm sorry, Paul..." (Participant 5, para 111).

4.5.2 "I'm not very good at looking after someone else..." - Concerns regarding the future of relationships

Three participants spoke generally about their concerns regarding the natural progression of intimate relationships. They appeared somewhat nervous about how they might cope in situations where others may become dependent on them or where their relationship shifts to a higher level of intimacy or inter-dependency:

"... whereas pair [implying intimate relationships and not friendship or familial relationships] relationships where it's all equal and you look after each other - I'm not very good at looking after someone else, I'm afraid. So no it would not work." (Participant 4 para 7).

Participant 2 talked about how in the initial stages of her relationships she was able to hide her difficulties from a partner. However, as the relationship progressed she felt this had become more challenging. She appeared to be suggesting that she wanted to hide her difficulties perhaps indicating a sense of embarrassment or apprehension with regard to how her difficulties might be perceived:

"But coming back to aspects of AS - when you are seeing somebody about once a week and he lives about 40 miles from here, you can kind of present a sanitised version of yourself, you could reign it in" (Participant 2 para 97).

Some of the participants also described concerns that they would end up co-habiting with an intimate partner. This seemed to relate to both a preference for living alone, and also a belief that potential partners would not be able to tolerate living with them. Both strands are captured in the quotations below:

“Nobody can live with me - I’m intolerable - well, I’ve been told that by my people that I’m close to. Even Roger said I was overbearing when I stayed with him for a few days! No, I’m very good when I meet people for just a couple of hours... when someone is around me for a too long time like for days on end, we get into each other’s pockets” (Participant 4 para 58).

“And sometimes it manifests itself in a way where one particular person who would tire of me would say ‘you don’t need a lover, you need a carer” (Participant 6 para 14).

“If someone moves in and suddenly there’s all these new noises and they’re driving me nuts and the expectation is, you just go with it. The expectation is, these are the noises that this new person makes. No, that’s not working, you’re driving me insane. It’s like finger nails on a [chalkboard]... the expectation is you just get over it but I can’t meet that expectation. So, for a lot of people that’s hard. I understand that I am no picnic to live with. I spend far too much time alone, I like things in a certain order. Things have to be a certain way and it’s rigid and there’s no flexibility with it” (Participant 7 para 73).

Another area, which concerned some of the participants, was their perception that intimate relationships would move to a point where they might be expected to think about having children. For example, Participant 2 talked about not feeling that she would be able to cope with children and consequently not wanting to have any:

“...but it’s not something I actually want because I am not sure what kind of parent I’d be. I would want to be a good parent” (Participant 2 para 93).

“I don’t not want to be a parent, though I don’t feel any particularly strong urge to be a parent. I mean, I like children but I am not sure I can cope with them” (Participant 2 para 95).

4.5.3 “It's what winning the lottery feels like...” - Positive aspects of relationships

Seven participants spoke about a number of areas that they enjoyed in their intimate relationships. One participant noticed a gesture made by her partner and described it as 'sweet':

“He also wanted to ask my Dad’s permission to, if my dad wasn’t there he would have asked my brother – quite old fashioned in that way, which is quite sweet... It’s like asking somebody’s father permission to court a woman - like 100 years ago! I thought it very sweet actually” (Participant 1 para 21).

She also reported enjoying the fact that her partner found her physically attractive:

“Stanley, I have seen him enjoying my appearance [giggling]. He saw me in my swim suit recently and he enjoyed that and he was ‘wow all very nice!’ That’s the difference!” (Participant 1 para 44).

Some participants spoke about the activities they enjoyed doing with their partners. These included: watching movies (Participant 3 para 36; Participant 1 para 31); going to the pub (Participant 1 para 1); treating each other (Participant 4 para 44); communicating on social networking websites (Participant 1 para 61); giving one another gifts (Participant 3 para 63); and listening to each other (Participant 1 para 52).

Participant 6 suggested that activities had more meaning if shared with others and that even seemingly meaningless activities could acquire meaning when experienced alongside a partner or potential partner:

“Where to begin? Um... music, TV shows, travel, um... stories, poems, jokes, random thoughts, all these things when experienced by just one person, they’re only ever have that one person's impression. Um... that’s kind of dull, they gain meaning and they gain sense when they are shared with other people and other people can link those experiences with their own. Um... that sounds massively philosophical and really quite meaningless...” (Participant 6 para 50).

“... and you get to share that with one another and it means that the world is twice as big, twice as colourful, twice as detailed...” (Participant 6 para 51).

Some participants described how intimate relationships provided them with a sense of having a safe space, in which they could be themselves as a person with ASD, and be comfortable with making the social mistakes that come with it. Participant 6 captures this in the quoted below:

“Uhm... yeah... if you can't make social mistakes around your partner then who can you really? I mean if you are sort of not doing it deliberately and depending on what sort of social mistake it is, if you're not... uhm... doing something absolutely 100% ridiculous like, I don't know, starting to sing 'My Old Man is a Dustman' at their father's funeral” (Participant 6 para 53).

“It's something about the way when I'm in love, I feel like it's ok to be myself which is something I don't feel the rest of the time which is sort of an enormous crushing self-doubt sort of sense of not being good enough...” (Participant 8 para 77).

Two participants shared feeling happy and good about themselves when in intimate relationships. These two participants describe their experiences of successful intimate relationships as though they were not a given in life, rather that these were an achievement despite their difficulties:

“It's like I always have this kind of incredible need to be in one... actually to be in love and absolutely want to be in a relationship and it's the only time that I really felt happy in my life and...” (Participant 8 para 63).

“When it all works it's amazing and it feels great and I feel really good about myself, it's like 'look I have a personal connection to the other living being'. I can do it like everyone else can. I can have this like everyone else can. I am not that abnormal that I cannot form a simple connection to another person. I can do this! That connection is amazing when that connection works, it's... I imagine it's what winning the lottery feels like” (Participant 7 para 91).

CHAPTER 5: Discussion

5.1 Introduction

This is a qualitative study using IPA methodology to capture the experiences of intimate relationships in adult women with a diagnosis of ASD. Eight participants were interviewed during the study. In summary, the analysis identified four overall themes. Each theme was made up of a number of sub-themes. The first theme was; Response to receiving the diagnosis and information about ASD, with three sub-themes, i.e. Emotional reaction to the diagnosis, Self-reflections since the diagnosis, and Improved understanding of themselves. The second theme was; Factors influencing dating behaviour with three sub-themes, i.e. Reasons to date, Reasons not to date, and Disclosing the diagnosis to partner/potential partners. The third theme was; Sex and sexual experiences, with three sub-themes, i.e. Sexuality, Difficulties relating to sex, and Negative sexual experiences. The final theme was labelled Experiences of relationships as a person with ASD, also with three sub-themes, i.e. Challenges experienced in relationships, Positive aspects of relationships, and Concerns regarding the future.

This chapter will consider the strengths and limitations of the study, and also provide a more general discussion of the results. It concludes with recommendations for the direction of future research and clinical implications of the results.

Some of the identified findings do not necessarily relate directly to the topic of intimate relationships were included as these have been identified as important issues by participants and were closely associated with the development and maintenance of intimate relationships.

5.2 Strengths and limitations of the study

To the current author's knowledge, this is the only research qualitative study to date attempting to understand the relational experience of women with ASD who have been diagnosed with the disorder in adulthood. It provides important new information on the lived experience of women with ASD, particularly in relation to intimate relationships in this population group.

The main strength of the study was that it focused on a population group who are often difficult to engage. Despite the low prevalence of women diagnosed with ASD in the general population, and the potential sensitivity of the subject, the recruitment method used allowed for access to a sufficient sample size. The current author took active steps to ensure that the participants were as comfortable as possible during the study. The first step involved ensuring that they were introduced to the study by a clinician with whom they were familiar and who explained to them that the current author would contact them about the study. This provided the participants with context for the research and the nature of the follow-up call from the author. Throughout contact with the participants the current author remained mindful of the difficulties participants could experience in setting up interview dates, attending the interview and the actual experience of the interview. The current author remained flexible with regard to all three of these areas; for example, participants were given the option of a number of choices as to where the interview could be conducted to ensure they felt comfortable. Interview times and the duration of the interviews were determined by the participants themselves.

Attempts were made to ensure that all participants had a formal diagnosis of ASD. Five of the participants were identified through clinicians who worked in an ASD diagnostic clinic where the participants had received their diagnosis. However, three of the participants were recruited through an on-line advertisement. These participants self-reported that they had a formal diagnosis (i.e. following a detailed assessment by a qualified clinician). Nevertheless, the results can therefore be considered reflective of the clinical population of women with ASD.

In studies using IPA methodology, it is generally accepted that the sample should be as homogenous as possible (Smith et al., 2010). The participants were homogenous in terms of age range as the study included women from a relatively narrow age range (25 years to 40 years). However, it was challenging to control for the variety of time periods since diagnosis. This may have impacted on the extent to which participants had developed insight into their ASD and consequently could have influenced discussion during the interview. The current relationship status of participants also varied, for example, one participant was married and had children, one was divorced and furthermore, diversity in their sexual orientation emerged. These factors may have reduced the homogeneity slightly, and could have confounded the results to some extent. In addition, the recruitment strategy was likely to have captured only those who actively sought out a diagnosis, were literate and had engaged in relationships at some point.

The variation in time lapses since diagnosis, relationship status and sexual orientation does allow for a broader range of views, as well as a better understanding of personal development and impact following a diagnosis of ASD. It is noted that some qualitative researchers prefer a more heterogeneous sample as this makes it more likely to be representative of the population group as a whole (Jenkins et al., 2001).

Some demographic and other details of participants were collected during the study. This helped to put findings into context. However, in hindsight it would have been useful to collect additional information to allow for a better understanding of some of the results. For example, it would have been useful to have a record of 'time since diagnosis' and 'level of post-diagnostic counselling' for each participant.

The design of the semi-structured interview schedule itself may have resulted in some areas being covered in less detail than others. However, the interview schedule was discussed with the research supervisors, who are both clinicians with considerable experience in working with individuals with ASD. Additionally, after the first interview, the interview schedule was shared with the research supervisors and adjustments were made in order to ensure it was in keeping with the research aims.

The results provide a detailed account of the participants' experience despite the interviewees having inherent communication and social communication difficulties. Additionally, due to the sensitive topic of research, the current author would have expected a level of reluctance in self-disclosure from the participants. However, this did not appear to be the case. It is possible that individuals with ASD are less able to detect discomfort in others due to their difficulty in picking up on non-verbal cues (Tantam, 2009; Baron-Cohen et al., 1985) and may therefore be more likely to disclose intimate details than individuals without ASD.

Finally, it is noted that each of the interviews took place in a different location, primarily the participants' homes. This may have impacted differently on each participant and so also on the current author. However, by conducting the interviews in an environment comfortable to each of the participants, their anxiety levels were reduced which improved the quality of the interviews.

5.3 Discussion of results

5.3.1 Response to receiving the diagnosis and information about ASD

Participants reported a range of responses to receiving the diagnosis of ASD in adulthood. A common feature was a sense of relief. This seemed to be related to the perception that the diagnosis provided a logical reason for previously experienced social and emotional difficulties. This finding is consistent with those of Punshon et al., (2009) and Young et al., (2008) who demonstrated similar narratives of relief in adults who were diagnosed with a developmental disorder in adulthood.

Individuals with ASD have social difficulties, which often lead to their behaviour being labelled as socially inappropriate; for example, as rudeness (Viding & Blakemore, 2006). Knowing about a formal diagnosis and the identified traits that warranted the diagnosis, could alter the perceptions that others have of an individual's behaviour as well as the perceptions a person has of herself (Tantam, 2000). Indeed, some participants stated that obtaining a diagnosis provided them, and others, with a rationale for their behaviour that may otherwise have been labelled as inappropriate.

Furthermore, participants reported that since being diagnosed, they had become more aware of how ASD may affect their personalities. This awareness manifested in a variety of ways. Some participants reported feeling more socially inhibited by the knowledge that they were prone to making social 'mistakes' or *faux pas*. For others it brought about a sense of loss or grief and even a sense of defeat because they felt that their difficulties were not likely to change. Other responses to the awareness of ASD traits included reflecting on past experiences, finding ways to accommodate their difficulties and being less critical of themselves. This is similar to findings of Young et al., (2008) who found that adults who received a diagnosis of ADHD in adulthood experienced a sense of acceptance and could therefore address the sense of failure that they had harboured. In this way, a formal diagnosis provided participants with a means to view their difficulties more rationally rather than being blamed for their shortcomings - this may have a positive impact on self-perception. Some participants reported that being aware of their strengths and weaknesses, helped them to identify coping strategies to compensate for some difficulties. This seemingly resulted in them feeling more in control, and consequently being able to engage more actively with their communities.

The mixed responses to being made aware of difficulties associated with ASD, could be attributed to the tension between becoming aware of specific difficulties, yet not always being able to use this insight to better navigate their social worlds. That is, having knowledge that you have difficulty interpreting social cues in itself, does not necessarily improve your ability to read social cues in practice (Hill & Frith, 2003). Participant 2 in the current study captured this well when she explained that hypothetical knowledge does not always equate to ability in practice:

“I can theoretically accept that something different is going on to what I think is going on – but by working out and by keeping in mind my interpretations, is something... I can think it, but not carry it out in practice” (para 123).

Participants also spoke more specifically about how having received a diagnosis of ASD impacted on their intimate relationships. Overall, as well as improving their own understanding of their difficulties, participants found that the diagnosis enabled them to explain their difficulties to others in the context of intimate relationships. Some participants found that their partners consequently made an extra effort to accommodate their needs, which was generally well received. However, one participant reported frustration because her partner only began to accommodate her difficulties following the diagnosis of ASD. Another participant reported that she felt that a better understanding as a result of the diagnosis was a disappointment to her partner as he became aware that her difficulties were most likely pervasive. It is clear from the above that alongside personal reactions to the diagnosis, it is important to support individuals with ASD - considering the impact on the dynamics of their personal relationships with others.

Some participants reported that since receiving information about their diagnosis and their increased understanding of their ASD related difficulties, they started questioning the accuracy of their perceptions of situations. The awareness that alternative perceptions of social interactions existed beyond one's own could be challenging. However, it could also be expected that most neuro typical people would continually, build on the ability to understand that there are different ways of perceiving situations, from an early age. Therefore, they would have had many opportunities to not only develop their tolerance for what they might not know, but also acquire skills for interpreting new situations. Those participants diagnosed relatively recently may not as yet have developed these skills, and could experience the awareness of an innate difficulty in interpreting social interactions as debilitating. Participant 5 provided an analogy for this by saying that before being diagnosed with ASD she felt that she was on a stage with no fear of being seen but since receiving the diagnosis, she experienced herself to be under the stage observing how to act. This may suggest

a need to offer support alongside a diagnosis, such as interventions to not only support the learning of skills to accommodate difficulties, but also to come to terms with the limitations of which they have only recently become aware.

Participants in the current study reported similar emotional responses to those participants in the studies by Punshon et al., (2009) and Young et al., (2008). However, in contrast to individuals diagnosed with ADHD, participants in the current study seemed to have experienced a range of emotional reactions in response to the diagnosis rather than following a linear process of emotional stages.

5.3.2 Factors influencing dating behavior

When talking about their reasons for dating, some participants in the current study talked about a sense of having asocial obligation to have intimate relationships. It may be common for people to feel this obligation, whether they have ASD or not. It is hypothesised by the author of the current study that the specific population group fell within an age range that placed them in a position of high exposure to societal narratives surrounding intimate relationships. This in turn may have heightened their awareness of social expectations in this area.

It could also be that people with ASD are more observant and interpretive of the behaviour of others than assumed through the use of popular media and utilizing this as a standard for what their own behaviour should look like. Using the interactions of others as a model for intimate relationships is unlikely to be successful, given the limited extent to which most individuals display the most intimate of relational interactions in a public forum. It is also likely that media representations may not truly reflect real-life relationships. This was perhaps best captured by Participant 2 who stated that if she had the option, she would want to observe others through the closet door in order to learn how to interact with others.

One of the participants in the current study talked about feeling that her mother had not been a positive role model for intimate relationships. From a psychodynamic perspective it is thought that individuals often model adult relationships on those they experienced as a child (Bowlby, 1988). It is hypothesised that perhaps individuals with ASD in particular, are in need of positive intimate relationships being modelled in their own families of origin as this often is the only setting within

which they could observe this type of social interaction. Without such positive relational modelling, some individuals could possibly have more relationship difficulties than their neuro-typical peers as they could be more dependent on observing others in order to obtain social skills. However, this is speculative and further empirical research would be required to establish whether individuals with ASD are more or less affected by early relational modelling than their neuro-typical peers.

A number of factors influenced whether or not participants in the current study engaged in intimate relationships. Participants were not sure when a potential partner showed interest in them. This may be directly related to the difficulties individuals with ASD have in comprehending subtle social cues and the unexpressed thoughts and emotions of others during interactions (Baron-Cohen et al., 1985; Tantam, 2009). This is also congruent with the findings of Sperry & Mesibov (2005) who noted that the lack of social and emotional understanding can compromise participation by people with ASD in more intimate relationships, including marriage. Simone (2010) took this a stage further, suggesting that women with ASD are more at risk of being mistreated in their intimate relationships than neuro-typical individuals as they are socially unskilled.

Some participants reported that their daily routines provided a barrier to dating. For example, one participant stated that she did not have time in her schedule for dating which prevented her from dating (Participant 3). It could also be hypothesised that this is a defensive strategy to protect against having to admit that dating is an area that evokes anxiety or a sense of hopelessness. Most participants expressed a wish to date and be in an intimate or longer-term relationship. Only two participants stated that they preferred not to have a partner. However, these participants were not completely against the possibility of dating. Perhaps the stated reasons not to date have a common underlying thread of experiencing difficulties in managing and a lack of confidence in the ability to establish and maintain intimate relationships.

As previously described, given the experiences of disclosing their diagnosis within the context of intimate relationships, it is perhaps not surprising that whilst some participants were clear that disclosing their diagnosis to current or potential intimate partners was important, some participants were reluctant to do so. This is an important consideration in view of the findings of Dindia & Timmerman (2003) who reported that the disclosure of personal information to a partner was a strong predictor of relationship satisfaction.

Some of the concerns related to disclosure of the ASD diagnosis and the barriers in doing so, included being found unattractive, being stigmatised, and being judged. This is perhaps in contrast to the ToM theory: Being aware of the stigmatising beliefs of others does require inferring the perceptions of others. In addition it could be hypothesised that being aware of stigmatising beliefs is a sophisticated awareness, as not only does it require inferring the mental states of others but also abstract social constructs.

One participant talked of her fear that potential partners would not engage beyond a superficial level with her due to their concerns that if they went on to have children together, they too might have ASD. It is possible that some of the participants were acting in accordance with their experience of, or worry about, the stereotyping and stigmatising of individuals with ASD. Goffman (1963) provided a notion of Social Stigma as having an attribute or behaviour that is socially disreputable. He suggested that the exhibition of the trait/behaviour and social response to it may lead to feelings of rejection or isolation. It is therefore possible that individuals with ASD would attempt to mask any traits they have that are susceptible to being stereotyped or stigmatised. Therefore, the way in which individuals with ASD are perceived by society, or at least their beliefs about this, could be a determining factor as to whether or not the diagnosis should be disclosed.

It is also reasonably common that in intimate relationships individuals will not fully disclose all of their character traits and self-perceived shortcomings, particularly in the beginning (Greene et al., 2006). However, people tend to disclose more of themselves as they get to know each other better. It is hypothesised that the reasons for deeper levels of self-disclosure and the timing of this, are likely to relate to a sense of social intuition within the relationship - which perhaps is not as easy for individuals with ASD (Baron-Cohen et al., 1985; Tantam, 2009). Therefore, people with ASD might have difficulties in assessing when might be the best time to disclose, as disclosure may require drawing on a range of contextual factors (Frith, 1989).

The above is further highlighted when taking into consideration the reasons for disclosure that were provided by participants; such as to gain support, to help others understand them, through feeling an obligation to disclose and to receive reassurance that a partner would remain interested despite the diagnosis. The decision of whether to disclose or not appeared to be dichotomous for some participants; either you do disclose or you do not without any indication that there was a possible continuum of disclosure or a range of points in a relationship when a disclosure could be made.

However, it should be noted that the conditions under which an individual might disclose their diagnosis, was not a direct question asked by the researcher and therefore a full understanding of this concept might not have been gained.

5.3.3 Sexuality and sexual experiences

All participants in the current study spoke about sex during the interviews. However, there was much variety in what they chose to discuss, as well as different views on sexual activity. This included that sex was a behaviour without much meaning, that it was an important quality of intimate relationships and that it was not something they were particularly interested in. It was also noted that participants described their sexuality as heterosexual, homosexual, a-sexual or demi-sexual. This variety of responses made it difficult to make specific inferences and it is unclear as to whether this is different from what would be found if discussing relationships with women without ASD.

Some participants reported that they experienced unpleasant sensory experiences during sex. An example of such experiences is reported by Participant 8. She explained that she accommodated this sensory sensitivity in a way that could be considered peculiar by her partner and others. This is perhaps in line with the Sensory Theory of Autism which would attribute behavioural and communication difficulties to sensory sensitivities (Bogdashina, 2013).

In addition to the difficulties some participants experienced, wondering about their sexuality and the negative sexual experiences they had in the past, could possibly account for an increased likelihood that this population group may have difficulty establishing a consistent gender identity. This could provide a hypothesis for the high than expected proportion of people with ASD who present at gender identity dysmorphic clinics (Robinow & Kudson, 2005). This could be further explored with individuals with ASD in subsequent studies.

Some of the participants in the current study reported having had negative sexual experiences. Their evaluation of these experiences was often made in hindsight; they described not realising the nature of the experience at the time, and at times feeling unable to act as a result. This is likely to reflect a similar pattern to what might be reported by some victims of sexually abusive experiences (Moore & Brown, 2006). However, it could be hypothesised that the struggles individuals with ASD have in reading situations and understanding communication, may increase their level of vulnerability. This

is supported in the wider literature which suggests that individuals with neuro-developmental difficulties are more likely to be sexually victimised (e.g. Martin et al., 2006).

Participants did not report on any positive experiences of sex. This is not to say they did not have any positive sexual experiences. Participants could have found it challenging to discuss positive sexual experiences with a professional who specifically approached them in order to talk about their diagnosis, which may have implied a need to restrict the discussion to their difficulties.

5.3.4 Experience of relationships as a person with ASD

When talking about their actual lived experience of relationships, participants reported a wide range of experiences. Many of these related to having difficulties in understanding a partner or potential partner's intent and their tendency to take things literally. This often appeared to result in confusing social interactions. Muller et al., (2008) also found this to be a theme in the experience of individuals with ASD in their study. In his original description of the core deficits of ASD, Kanner (1943) identified a lack of acknowledgement of others and difficulty in understanding non-verbal communication; including gestures, facial expressions and body language. It has been demonstrated that a large percentage of communication is displayed or implied rather than explicitly stated and that this type of communication can often be subtle (Knapp et al., 2013). Despite the difficulties in interpreting non-verbal communication identified in individuals with ASD, some of the participants in the current study demonstrated an understanding of, and ability to reflect on subtle social interactions. This demonstration is perhaps in contrast with the ToM theory (Baron-Cohen, 1985). Their difficulty often seemed to stem from being unsure about how to respond to or accurately interpret these subtle non-verbal communications rather than a lack of awareness that they existed.

The hypothesis given above perhaps provides a reason for the difficulties that participants reported in having to manage conflict within their intimate relationships. It could be deduced that if one struggled to understand body language, had a tendency to interpret spoken language literally and was unable to infer the intent of others, then it might be difficult to successfully negotiate conflict. Somewhat related to this was the description given by some participants of their difficulties to consider the perspective of their partner/potential partner in any given situation. They seemed to suggest having difficulties in understanding that others think independently from them. This apparently extended to positive communications, with some participants reporting that they did not

always comprehend some of their partner's behaviour when the underlying intent was care or affection. This however does fit well with the ToM explanation of ASD related deficits (Baron-Cohen et al., 1985). Deficits in ToM may lead to difficulties in understanding and validating a partner, both of which are considered important for high levels of relationship satisfaction (Reis, 2007).

Another difficulty that participants had in the negotiation of conflict was the concept of passive aggressive behaviour from their partner. This is a complex form of communication. The success of interpreting this communication depends on the ability of another party to understand implied intent that is not directly given in the spoken or observed language. Communication difficulties and conflict could overlap as people with ASD communicate based on a set of rules and understanding, which may not be responsive to the emotionally charged and dynamic nature of conflict (Myles & Simpson, 2001). Sperry & Mesibov (2005) provided a useful summary of this when they stated that people with ASD desired relationships but that the lack of skills and fluency in social interaction may hinder their efforts to initiate and sustain relationships.

Participants spoke about other difficulties in managing intimate relationships caused by the spontaneous and idiosyncratic nature of relationships, and the absence of a specific set of 'rules'. Many of the participants spoke about preferring structure and routine in their relationships and the behaviour of those around them, thereby potentially attempting to increase the predictability of their physical and social surroundings. This suggests a paradox between wanting a relationship but being unlikely to achieve this due to the level of structure and predictability they reported to prefer, which is consistent with the findings of Muller *et al.*, (2008) who stated that their participants voiced the desire to have and maintain relationships but feared not knowing what it might entail. The need for structure and routine reported by participants in the current study extended to individual interactions within their relationships. Pennington (2003) highlighted that individuals with ASD found it difficult to converse when there was no clear structure to a conversation. This is likely to pose a difficulty for individuals with ASD taking into consideration that a large part of relationship development may involve spontaneous and unstructured conversation.

When describing their experiences within intimate relationships, some of the participants talked about activities and communication with their partners that may be suggestive of enjoying the element of reciprocity within the relationships, for example talking to each other, listening to each other, the sharing of gifts and appreciating each other. This is perhaps in contrast to what might be expected from individuals with ASD as they are often thought to be self-focused due to deficits in

ToM (Baron-Cohen et al., 1985). Upon further analysis, it became apparent that it was the participants who had been in long-term relationships and who had experience of disclosing their diagnoses, and who spoke about these elements of reciprocity. This may suggest that, where difficulties are better understood and strategies are developed to accommodate these, individuals with ASD have the opportunity to develop genuine reciprocal relationships. It is noted though, that the current study is unable to provide this as a conclusion and further research would be required to explore this point. Perhaps this could involve specifically selecting participants at varying time lapses since diagnosis.

In relation to the above, some of the participants appeared to demonstrate some apprehension as to remaining in a relationship long enough to allow the above process to develop. In these cases, these participants appeared to describe a sense of concern as to how they might manage the natural progression of relationships. For example, being able to conceal difficulties related to ASD, feeling that they would struggle to co-habit and that others would struggle to co-habit with them, and managing their partner wanting to take relational steps that they did not feel ready for, such as having children.

5.4 Recommendations for future research

This research study is one of the first to qualitatively explore intimate relationships in women with ASD and may contribute to the development of understanding in this area. Future studies could build on gaining a fuller understanding of the lived experience of women with ASD. It may be possible to use some of the findings from the current study to conduct a more focused study, which could explain and expand on the identified themes.

The current research findings suggest that there may be commonalities between the experiences of women with ASD in intimate relationships, and the experiences of neuro-typical women. It may be that these two population groups can only be differentiated by the effort it takes to interpret and understand social communication. In other words; making, establishing and maintaining intimate relationships are potentially more effortful for individuals with ASD than for their neuro-typical peers. It may be interesting to undertake a comparative study to explore specific difficulties of women with ASD.

The level of understanding of ASD differed across participants. It is not possible to tell from the current study the extent to which their understanding was established post diagnosis. It may be useful to develop some way of measuring changes in understanding pre and post diagnosis. This could facilitate an understanding of the specific impact of the diagnosis and inform any post-diagnostic counselling that focuses on intimate relationships. Punshon et al., (2009) found that participants' beliefs about the disorder were crucial to their adjustment to the diagnosis. This perhaps highlights the need for additional interventions following a diagnosis of ASD.

5.5 Implications for clinical practice

The current study has highlighted a number of areas where individuals with ASD may benefit from psychotherapeutic input. It seems that there may be some benefit to providing post-diagnostic counselling with a specific focus on intimate relationships, both for individuals who are in relationships and those who want to pursue relationships. This should aim to include elements designed to increase insight into the likely challenges they may face, making sense of past relational difficulties, preparing for and developing/practising skills likely to be useful in the initiation and maintenance of intimate relationships.

The findings of the current study may support clinicians when thinking about informing an individual of a diagnosis of ASD, particularly if the participant is in an existing relationship. It may also have implications for relationship counselling where the objective often is to assist in maintaining an intimate relationship. It may be useful to take a more systemic approach to this type of clinical work, which includes the partner in any intervention to support in the couple's development.

Navigating and understanding ASD in the context of intimate relationships, could pose a challenge to both partners; there is frequent misinterpreting of cues and behaviour on both parts, sometimes leading to resentment and confusion. This, as suggested by participants in the current research, can lead to difficulties in establishing and maintaining intimate relationships. Therefore it may also be useful to consider including or offering separate support to partners of individuals with ASD in psychotherapeutic work.

Psychotherapeutic input may also help individuals with ASD to come to accept some of the inherent difficulties and paradoxical feelings they may experience. This in itself may be of therapeutic benefit

to some individuals. For example, having a need for social relationships but at the same time finding them tiring, needing respite and feeling lonely as a result thereof:

“... there’s a sort of weird kind of a thing that goes on where like that self-focus and the loneliness are almost kind of part of the same thing... why have this incredibly strong almost addictive like drive to be by myself, and yet feel this like enormously crushing loneliness at the same time... I just don’t understand how they kind of can be reconciled... it’s kind of being pulled into two directions at once...” (Participant 8).

5.6 Conclusion

The women who participated in the current study, for the most part wanted to engage in intimate relationships. They often found this challenging; leading to them feeling that they were unable to initiate or to sustain these relationships. Many of the experiences described by the women in this study were congruent with what the researcher assumes would be common for neuro-typical individuals in the establishment and maintenance of intimate relationships. However, the lack of understanding of non-verbal communication appeared to compound many of the reported difficulties and their ability to negotiate them. Having an awareness of the difficulties and how they might impact on intimate relationships, may support these women in achieving greater satisfaction in this area of their lives.

5.7 Author’s response to the research

I experienced several emotional responses during the process of conducting this research, analysing the data and writing about it. In this section I shall reflect on some of these responses which I considered to be the most significant. These are documented in the order in which the research was conducted; i.e. the interviews, analysis, and revisiting the data.

5.7.1 The Interviews

The interview itself brought about challenges, and required a shift from my natural position as trainee psychologist to that of researcher. I needed to be mindful so as not to contaminate the interview with interventions, reassurances or addressing distorted beliefs. The role of the current author required taking more of an investigatory stance to elicit the experience of the participant. This awareness was brought about when Supervisors commented on my stance, after reading the interview transcript. Consequently, this enabled me to adjust my stance to some extent in the following interviews.

5.7.2 The Analysis

I was surprised by the extent to which the participants participated in the research. It was difficult to schedule interview dates with some of the participants and based on this difficulty, I assumed that the potential participants experienced some hesitation or anxiety in meeting with me. However, during the interviews the participants co-operated and responded very generously, providing a rich account of their dating experience. I was aware throughout that I could not offer the participants much in return and I experienced a sense of responsibility towards the participants, which resulted in having to face two main challenges:

Firstly, I found it challenging and even frustrating to prioritise the data in such a way that addressed specifically the research question. The participants spoke about many important matters but this was not always within the scope of the study and therefore some of the content has not been included. My response to the data brought about a feeling of responsibility. The population group in this study could be hard to reach. The research reveals much of the needs of the women and their struggles in relationships. To some extent, these issues could have implications for both service provision and further research.

Secondly, I also found it challenging to walk the line between staying close enough to the narrative of the participants and simultaneously allowing myself some scope for interpretation. This process was helped by being mindful of both my chosen epistemological stance and the chosen method, both allowing some scope for interpretation.

Another response to the data was that the experiences of the women of their relationships or the lack thereof, was similar to how I experienced my own personal relationships, and the experiences of my female friends; for example, trying to assess someone else's interest, pondering on the progression of the relationship, finding ways to manage conflict effectively and being subjected to communication gaps. The aspects of relationships enjoyed by participants were also similar to those which I enjoyed and those enjoyed by my friends. I found these similarities unexpected. However, the differentiating factor lies in the extent to which these difficulties hinder us from initiating and maintaining relationships. I was mindful of not simply over-normalising these experiences, so as not to overlook the extent to which these difficulties were experienced by the participants with ASD.

5.7.3 Revisiting the Data

Towards the completion of this research study, I re-read the accounts several times and re-considered the analysis. In doing so, I became aware of having different responses to the data and found myself re-analysing the data based on the knowledge and experiences I had accumulated since the previous time of reading the study. Therefore, an overwhelming response to the data is the subjective and contextual nature of qualitative research. In addition to my growing understanding of the data I was strongly reminded that the data was obtained within a certain context; the participants shared their experiences based on the physical situation in which we found ourselves during the interview and their experiences and outlook at the time of the interviews. Therefore, if they were to read this study, their own understanding of their own experiences might change and be interpreted differently.

5.8 Summary

The aim of this thesis was to investigate the experience of intimate relationships of women who were diagnosed with ASD in adulthood. The first hurdle was to determine which methodology would best support the research question whilst providing scientific validity - and also for the current author to be reflective about her own epistemological stance. The current author's view was that any attempt to narrate or interpret another's experience would always be filtered through her (the current author) own cognitive schemas. Although some may argue that that these schemas could be 'bracketed', the current author believed that it was important to reconcile the participants' interpretation of their experiences with the understanding and interpretation of the current author. From this position, efforts were made to be reflective and transparent about how the data was interpreted. IPA methodology seemed to best lend itself to the abovementioned aims.

The IPA methodology followed the recommendations of predominant authors in the field of IPA and in line with these, the study had relatively specific inclusion criteria and therefore also a small sample size. Participants were interviewed using semi-structured interviews. Following the interviews the data was transcribed verbatim and analysed.

From the current author's perspective, the analysis revealed four overall themes within the data, i.e. Response to receiving the diagnosis and information about ASD, Factors influencing dating behaviour, Sex and sexual experiences and Experiences of relationships as a person with ASD. Overall, the participants had mixed responses to receiving the diagnosis but in general, found it helpful to have a reason for their difficulties. Participants experienced many varying difficulties in dating but in general, expressed a desire to be in relationships. In relationships they experienced some positive and some negative aspects, some of which they attributed to their ASD related difficulties. The result of the analysis should be considered within the context of the methodological strengths and limitations. Finally, it is noted that whilst this study goes some way toward illustrating the experiences of women with ASD in relation to intimate relationships, further research is required in order to gain a more comprehensive understanding that is specific to women with ASD.

Bibliography

- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders: DSM-IV-TR*. Washington, DC, American Psychiatric Association.
- American Psychiatric Association. (2014). *Diagnostic and statistical manual of mental disorders: DSM-5-TR*. Washington, DC, American Psychiatric Association.
- Asperger, H. (1944). 'Autistic psychopathy in childhood.' In U. Frith (ed.) (1991). *Autism and Asperger's Syndrome*, pp. 37-92. Cambridge: Cambridge University Press.
- Auster, C.J. & Ohm, S.C. (2000). Masculinity and femininity in contemporary American society: a reevaluation using the Bem Sex Role Inventory. *Sex Roles*, 43(7/8): 499-528.
- Baker, A. E. Z., Lane, A., Angley, M. T. & Young, R.L. (2008). The relationship between sensory processing patterns and behavioural responsiveness in Autistic Disorder: A pilot study. *Journal of Autism Developmental Disorder*, 38:867-875.
- Baron-Cohen, S., Leslie, A.M. & Frith, U. (1985). Does the autistic child have a 'theory of mind'? *Cognition*. 21(1): 36-46.
- Baron-Cohen, S., Wheelwright, S., & Hill, J. (2001). The "Reading the Mind in the Eyes" test revised version: A study with normal adults, and adults with Asperger syndrome or high-functioning autism. *Journal of Child Psychology and Psychiatry*, 42: 241-252.
- Baron-Cohen, S., Wheelwright, S., Hill, J., Raste, Y. & Plumb, I. (2001). The "Reading the Mind in the Eyes" Test, revised version: a study with normal adults with Asperger Syndrome or high-functioning autism. *Journal of Child Psychology and Psychiatry*, 42(2): 241-251.
- Bateman, A. and Fonagy, P. (2009). Randomised controlled trial of outpatient mentalisation-based - treatment versus structured clinical management of for borderline personality disorder. *The American Journal of Psychiatry*, 166 (12): 1355-1364.
- Blackshaw, A. J., Kinderman, P., Hare, D. J., & Hatton, C. (2001). Theory of mind, causal attribution and paranoia in Asperger syndrome. *Autism*, 5(2): 147-163.
- Bogdashina, O. (2013). Sensory theory in Autism makes sense: A brief review of the past and present research. *OA Autism*, 1(1): 1-7.
- Bowlby, J. (1988). *A secure base: Clinical applications of attachment theory*. London: Routledge Classics.
- Bundy, A.C., Lane, S.J., Murray, E.A. & Fisher, A.G. (2002). *Sensory integration: Theory and practice*. Philadelphia: F.A. Davis Company.
- Byers, E.S & Nichols, S. (2014). Sexual Satisfaction of High-Functioning Adults with Autism Spectrum Disorder. *Sexuality & Disability*, 32: 365-382.
- Byers, E.S., Nichols, S. & Voyer, S.D. (2013). Challenging Stereotypes: Sexual functioning of single adults with high functioning autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 43(11): 2617-2627.

Castelli, F., Frith, C., Happe, F. & Frith, U. (2002). Autism, Asperger syndrome and brain mechanisms for the attribution of mental states to animated shapes. *Brain*, 125(8): 1839 -1849.

Centers for Disease Control and Prevention. Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010. *MMWR Surveillance Summaries* 2014, 63(SS02): 1-21. Available at <http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6302a1.htm?scid=ss6302a1w>. [Accessed on 8 March 2015].

Coie, J. D., Terry, R., Zakriski, A., Lochman, J., & McCord, J. (1995). 'Early adolescent social influences on delinquent behavior'. In McCord (Ed.) *Coercion and punishment in long-term perspectives*, pp. 229-244. Cambridge University Press: New York.

Cook, F., Ciorciari, J., Varker, T. & Devilly, G.D. (2009). Changes in long term neural connectivity following psychological trauma. *Clinical Neurophysiology*, 120(2): 309–314.

Corcoran, R, Cahill, C. & Frith, C. (1997). The appreciation of visual jokes in people with schizophrenia: A study of 'mentalizing' ability. *Schizophrenia Research*, 24(3): 319- 327.

Critchley, H.D., Daly, E.M., Bullmore, E.T., Williams, S.C., Van Amelsvoort, T., Robertson, D.M., Rowe, A., Phillips, M., McAlonan, G., Howlin, P., and Murphy, D.G. (2000). The functional neuroanatomy of social behaviour: changes in cerebral blood flow when people with autistic disorder process facial expressions. *Brain*, 123: 2203- 2212.

Dickie, V. (2003). Data analysis in qualitative research: a plea for sharing the magic and the effort. *American Journal of Occupational Therapy*, 57(1): 49-56.

Dindia, K. & Timmerman, L. (2003). 'Accomplishing romantic relationships'. In J.O. Greene & B.R. Burleson (Eds.) *Handbook of communication and social interaction skills*, pp. 685-721. Mahwah, New Jersey: Lawrence Erlbaum Associates.

Erikson, E.H. (1968). *Identity: Youth and Crisis*. (No. 7). New York: WW Norton & Company.

Findling, R. (2005). Pharmacologic treatment of behavioral symptoms in autism and pervasive developmental disorders. *The Journal of Clinical Psychiatry*, 66(10): 26–31.

Finlay, L. (2006). 'Rigour', 'Ethical Integrity' or 'Artistry'? Reflexively Reviewing Criteria for Evaluating Qualitative Research. *The British Journal of Occupational Therapy*, 69(7): 319-326.

Fombonne, E. (2005). Epidemiology of autistic disorder and other pervasive developmental disorders. *The Journal of Clinical Psychiatry*, 66(10): 3-8.

Fonagy, P., Bateman, A.W., Lorenzini, N. and Campbell, C. (2014). Development, Attachment and Childhood Experiences. In J.M. Oldham, A.E. Skodol and D.S. Bender (eds.) *The American Psychiatric Publishing Textbook of Personality Disorders* (2nd ed.), pp. 55-77. Arlington, Virginia: American Psychiatric Publishing.

Frith, U. & Happé, F. (1994). Autism: Beyond "theory of mind". *Cognition*, 50(1-3): 115-132.

Frith. U. (1989). *Autism: Explaining the enigma*. Oxford: Blackwell.

Gadamer, H. G. (1975). *Truth and Method*. London: Continuum.

- Ghaziuddin, M., Ghaziuddin, N., & Greden, J. (2002). Depression in persons with autism: Implications for Research and Clinical Care. *The Journal of Autism and Developmental Disorders*, 32(4): 299-306.
- Gilmour, L., Schalomon, P.M., & Smith, V. (2011). Sexuality in a community based sample of adults with autism spectrum disorder. *Research in Autism Spectrum Disorders*, 6(1): 313-318.
- Giorgi A. (2011). IPA and Science: A Response to Jonathan Smith. *Journal of Phenomenological Psychology*, 42(2): 195-216.
- Giorgi, A. (2010). Phenomenology and the practice of science. *Existential Analysis: Journal of the Society for Existential Analysis*, 21(1): 3-22.
- Glaser, B. G. & Strauss, A. L. (1967). *The Discovery of Grounded Theory: Strategies for qualitative research*. Chicago: Aldine Publishing Company.
- Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs, New Jersey: Prentice-Hall.
- Greene, K., Derlega, V. J., & Mathews, A. (2006). 'Self-disclosure in personal relationships'. In A. Vangelisti & D. Perlman (Eds.) *Cambridge handbook of personal relationships*, pp. 409-427. Cambridge: Cambridge University Press.
- Reis, H. (2007). Steps toward the ripening of relationship science. *Personal Relationships*, 14(1): 1–23.
- Henault, I. (2005). 'Sexual Relationships' In L. Baker & L. Welkowitz (Eds.) *Asperger's Syndrome: Intervening in Schools, Clinics and Communities*, pp.245-55. Hillsdale, New Jersey: Lawrence Erlbaum Associates.
- Hill, E.L. & Frith, U. (2003). Understanding autism: insights from mind and brain. *Philosophical Transactions of the Royal Society of London B: Biological Sciences*. 358: 281–289.
- Hobson, R.P. (2010). Explaining autism: Ten reasons to focus on the developing self. *Autism*, 14(5): 391-407.
- Hofvander, J., Delorme, R., Chaste, P., Nydén, A., Wentz, E., Ståhlberg, O., Herbrecht, E., Stopin, A., Anckarsäter, H., Gillberg, C., Råstam, M. and Leboyer, M. (2009). Psychiatric and psychosocial problems in adults with normal-intelligence autism spectrum disorders. *BMC Psychiatry*, 9(1): 35.
- Hogg, M.A., Terry, D.J. & White, K.M. (1995). 'A Tale of Two Theories: A Critical Comparison of Identity Theory with Social Identity Theory'. *Social Psychology Quarterly*, 58(4): 255-269.
- Holloway, I. and Todres, L. (2003). The status of method: Flexibility, consistency and coherence. *Qualitative Research*, 3 (3): 345-357.
- Howard, B., Cohn, E. & Orsmond, G.I. (2006). Understanding and negotiating friendships: Perspectives from an adolescent with Asperger syndrome. *Autism*, 10 (6): 619-627.
- Howitt, D and Cramer, D. (2011). *Introduction to research methods in psychology* (3rd Ed.) Harlow: Pearson Education.
- Howlin, P. (2000). Outcome in adult life for more able individuals with autism or Asperger syndrome. *Autism*, 4(1): 63-83.

- Howlin, P. & Moore, A. (1997). The diagnosis of autism and Asperger's syndrome: Findings from a survey of 770 families. *Developmental Medicine and Child Neurology*, 41(12): 834-839.
- Howlin, P., Magiati, I. & Charman, T. (2009). Systematic Review of Early Intensive Behavioral Interventions for Children with Autism. *American Journal on Intellectual and Developmental Disabilities*, 114(1): 23-41.
- Johnson-Ecker, C.L. & Parham, L.D. (2000). The evaluation of sensory processing: A validity study using contrasting groups. *The American Journal of Occupational Therapy*, 54(5): 495-503.
- Jenkins, V., Fallowfield, L. & Saul, J. (2001). Information needs of patients with cancer: results from a large study in UK cancer centres. *British Journal of Cancer*, 84(1): 48-51.
- Jones, R.S.P. & Meldal, T.O. (2001). 'Social Relationships in Asperger's Syndrome: A qualitative analysis of first-hand accounts'. *Journal of Learning Disabilities*, 5(1): 35-41.
- Kanner, L (1943). Autistic disturbances of affective contact. *Nervous Child*, 2: 217-250.
- Kerr, K. (2007). Romantic Relationships and Autism Spectrum Disorder. *Autism Victoria* [online]. Reviewed and updated April 2011. Available at <http://www.amaze.org.au/uploads/2011/08/Fact-Sheet-Romantic-Relationships-ASD-Aug-11.pdf>. [Accessed on 2 February 2015].
- Knapp, M., Hall, J. & Horgan, T. (2013). *Non-verbal communication in human interaction* (8th Ed.) Wadsworth: Cengage Learning.
- Langdrige, D. (2007). *Phenomenological Psychology: Theory, Research and Method*. England: Pearson Education.
- Larkin, M., Watts, S. & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology*, 3(2): 102-120.
- Lawson, W. (2001). *Life Behind Glass: A Personal Account of Autism Spectrum Disorder*. London: Jessica Kingsley Publishers.
- Levy, F. (2007). Theories of Autism. *Australian and New Zealand Journal of Psychiatry*, 41(11): 859-868.
- Liggett, H. (1997). Stars are not born: an interpretive approach to the politics of disability. In L. Barton and M. Oliver (Eds.) *Disability Studies: Past, Present and Future*, pp. 178-194. Leeds: The Disability Press.
- Lopez, C., Tchanturia, K., Stahl, D. & Treasure, T. (2008). Central coherence in eating disorders: a systematic review. *Psychological Medicine*, 38(10): 1393- 1404.
- Martin, S.L., Ray, N., Sotres-Alvarez, D., Kupper, L.L., Marocco, K.E., Dickens, P.A., Scandlin, D. & Gizlice, Z. (2006). Physical and sexual assault of women with disabilities. *Violence against Women*, 12(9): 823-837.
- McKlean, T.A. (1998). 'A Personal Account of Autism' in E. Schopler, G.B. Mesibov & K.J. Kunce (Eds.) *Asperger Syndrome or High Functioning Autism?*, pp. 345-356. New York: Plenum.
- Messman-Moore, T.L. & Brown, A.L. (2006). Risk perception, rape, and sexual re-victimization: A prospective study of college women. *Psychology of Women Quarterly*, 30(2): 159-172.

- Milton, M. (2005). 'Political and ideology issues'. In E. van Deurzen and C. Arnold-Baker (Eds.) *Existential perspectives on human issues: A handbook for therapeutic practice*. Basingstoke: Palgrave Macmillan.
- Muller, E., Schuler, A. & Yates, G.B. (2008). Social challenges and supports from the perspective of individuals with Asperger syndrome and other autism spectrum disabilities. *Autism*, 12(2): 173-190.
- Murphy, N. & Young, P. (2005). Sexuality in Children and Adolescents with Disabilities. *Developmental Medicine and Child Neurology*, 47(9): 640-644.
- Myles, B. & Simpson, R. (2001). Understanding the hidden curriculum: An essential social skill for children and youth with Asperger syndrome. *Intervention in School & Clinic*, 36(5): 279-286.
- Pennington, G. (2003). 'On Being a Woman'. In J. Kearns Miller (Ed). *Women from another planet: Our lives in the universe of autism*, pp. 253-254. Bloomington: Dancing Minds.
- Persico, A.M. & Bourgeron, T. (2006). Searching for ways out of the autism maze: genetic, epigenetic and environmental clues. *Trends in Neurosciences*, 29(7): 349-358.
- Punshon, C., Skirrow, P. and Murphy, G. (2009). The "Not Guilty Verdict": Psychological reactions to a diagnosis of Asperger Syndrome in adulthood. *Autism*, 13(3): 265-283.
- Reid, K., Flowers, P. and Larkin, M. (2005). Exploring lived experience: An introduction to Interpretative Phenomenological Analysis. *The Psychologist*, 18(1): 20-23.
- Reynolds, F. (2003). Exploring the meanings of artistic occupation for women living with chronic illness: a comparison of template and interpretative phenomenological approaches to analysis. *British Journal of Occupational Therapy*, 66(12): 551-558.
- Robertson, A.E. & Simmons, D. R. (2015). The sensory experience of adults with autism spectrum disorder: A qualitative analysis. *Perception*, 44: 569-586.
- Robinow, O. & Knudson, G. (2005). *Asperger's disorder and GID*. Paper presented at the XIX Biennial symposium of the Harry Benjamin International Gender Dysphoria Association (2005).
- Rosenthal, R. & Jacobson, L. (1968). *Pygmalion in the classroom: teacher expectation and pupils' intellectual development*. New York: Holt, Rinehart & Winston.
- Russell, T.A., Schmidt, U., Doherty, L., Young, V. & Tchanturia, K. (1999). Aspects of social cognition in anorexia nervosa: Affective and cognitive theory of mind. *Psychiatry Research*, 168(3): 181-185.
- Rutherford, M., Baron-Cohen, S. & Wheelwright, S. (2002). Reading the mind in the voice: A study with normal adults and adults with Asperger syndrome and high functioning autism. *Journal of Autism and Developmental Disorders*, 32(3): 189-194.
- Sanders, J. L. (2009). Qualitative or quantitative differences between Asperger's disorder and autism? Historical considerations. *Journal of autism and developmental disorders*, 39(11): 1560-1567.
- Sarbin, T. R. (1986). 'Emotions as narrative emplotments'. In M. J. Packer and R. B. Addison (Eds.) *Entering the circle: Hermeneutic Investigation in psychology*, pp. 185-201. Albany, New York: State University of New York Press.

- Scheeren, A.M., Begeer, S., Banerjee, R., Terwogt, M.M. & Koot, H.M. (2010). Can You Tell Me Something About Yourself? Self-Presentation in Children and Adolescents with High Functioning Autism Spectrum Disorder in Hypothetical and Real Life Situations. *Autism*, 14(5): 457-453.
- Schultz, R., Gauthier, I, Klin, A, et al. (2000). Abnormal ventral temporal cortical activity during face discrimination among individuals with autism and Asperger syndrome. *Archives of General Psychiatry*, 57(4): 331-340.
- Simone, R. (2010). *Aspergirls: Empowering Females with Asperger Syndrome*. London: Jessica Kingsley Publishers.
- Smith J.A, Flowers, P. and Larkin, M. (2010). *Interpretative phenomenological analysis: Theory, Method and Research*. London: Sage Publications.
- Soraya, L. (2008). Asperger's Diary- Life through the lens of Asperger's Syndrome. *Autistic Aloneness: When Coping Mechanisms Go Bad* [online] Available at: <<http://www.psychologytoday.com/blog/aspergers-diary/200805/autistic-aloneness-when-coping-mechanisms-go-bad>> [Accessed on 6 February 2012].
- Sperry, L.A. & Mesibov, G.B (2005). Perceptions of Social Challenges of Adults with Autism Spectrum Disorder. *Autism*, 9(4): 362-376.
- Spinneli, E. (1989). *The Interpenetration World: An Introduction to Phenomenological Psychology*. London: Sage Publications.
- Swango-Wilson, A. (2008). Caregiver Perceptions of Sexual Behaviours of Individuals with Intellectual Disabilities. *Sexuality and disability*, 26(2): 75-81.
- Tantam, D. (1988). Asperger's syndrome. *Journal of Child Psychology and Psychiatry*, 29(3): 245–255.
- Tantam, D. (2000). Psychological Disorders in Adolescence and Adults with Asperger Syndrome. *Autism*, 4(1): 47-62.
- Tantam, D. (2009). *Can the world afford Autistic Spectrum Disorder?* London: Jessica Kingsley Publishers.
- Tarnai, B. & Wolfe, P. (2008). Social Stories for Sexuality Education for Persons with Autism/ Pervasive Developmental Disorder. *Sexuality and Disability*, 26(1): 29-36.
- Thomas, D. R. (2006). A general inductive approach for analysing qualitative evaluation data. *American Journal of Evaluation*, 27: 237–246.
- Tonge, B.J., Brereton, A.V., Gray, K.M. & Stewart, L.E. (1999). Behavioural and Emotional Disturbance in High-Functioning Autism and Asperger's Syndrome. *Autism*, 3(2): 117-130.
- Van Deurzen, E. (2010). *Everyday Mysteries: A Handbook of Existential Psychotherapy* (2nd Ed.) London: Routledge.
- Viding, E. & Blackmore, S.J. (2006). Endophenotype Approach to Developmental Psychopathology: Implications for Autism Research. *Behavioural Genetics*, 37: 51-60.
- Warnock, M. (1970). *Existentialism (Rev. Ed.)* Oxford: Oxford University Press.
- Willig, C. (2008). *Introducing qualitative research in psychology* (2nd Ed.) New York: Open University Press.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health*, 15(2): 215-228.

Yardley, L. (2008). 'Demonstrating validity in qualitative psychology'. In J.A. Smith (Ed.) *Qualitative psychology: A practical guide to research methods*, pp. 235-251. London: Sage Publications.

Yeragani, V.K., Cashmere, D., Miewald, J., Tancer, M. & Keshavan, M.S. (2006). Decreased coherence in higher frequency ranges (beta and gamma) between central and frontal EEG in patients with schizophrenia: A preliminary report. *Psychiatry Research*, 141(1): 53–60.

Young, S., Bramham, K. & Rose, E. (2008). The experience of receiving a diagnosis and treatment of ADHD in adulthood: A qualitative study of clinically referred patients using interpretative phenomenological analysis. *Journal of Attention Disorder*, 11(4): 493-503.

Zucker, K.J., & Lawrence, A.A. (2009). Epidemiology of Gender Identity Disorder: Recommendations for the Standards of Care of the World Professional Association for Transgender Health. *International Journal of Transgenderism*, 11(1): 8-18.

Appendices

Appendix 1 – NHS ethics approval

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please enter a short title for this project (maximum 70 characters)

The Impact of Diagnosis of AS on Women's Expectations of Relationships

1. Is your project research?

☒ Yes ☐ No

2. Select one category from the list below:

- ☐ Clinical trial of an investigational medicinal product
- ☐ Clinical investigation or other study of a medical device
- ☐ Combined trial of an investigational medicinal product and an investigational medical device
- ☐ Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
- ☐ Basic science study involving procedures with human participants
- ☐ Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
- ☒ Study involving qualitative methods only
- ☐ Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
- ☐ Study limited to working with data (specific project only)
- ☐ Research tissue bank
- ☐ Research database

If your work does not fit any of these categories, select the option below:

☐ Other study

2a. Please answer the following question(s):

- a) Does the study involve the use of any ionising radiation? ☐ Yes ☒ No
- b) Will you be taking new human tissue samples (or other human biological samples)? ☐ Yes ☒ No
- c) Will you be using existing human tissue samples (or other human biological samples)? ☐ Yes ☒ No

3. In which countries of the UK will the research sites be located? *(Tick all that apply)*

- ☒ England
- ☐ Scotland
- ☐ Wales
- ☐ Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

- ☒ England
☐ Scotland
☐ Wales
☐ Northern Ireland
☐ This study does not involve the NHS

4. Which review bodies are you applying to?

- ☒ NHS/HSC Research and Development offices
☐ Social Care Research Ethics Committee
☒ Research Ethics Committee
☐ National Information Governance Board for Health and Social Care (NIGB)
☐ Ministry of Justice (MoJ)
☐ National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

5. Will any research sites in this study be NHS organisations?

- ☒ Yes ☐ No

5a. Are all the research costs and infrastructure costs for this study provided by an NIHR Biomedical Research Centre, NIHR Biomedical Research Unit, NIHR Collaboration for Leadership in Health Research and Care (CLAHRC) or NIHR Research Centre for Patient Safety & Service Quality in all study sites?

- ☐ Yes ☒ No

If yes, NHS permission for your study will be processed through the NIHR Coordinated System for gaining NHS Permission (NIHR CSP).

5b. Do you wish to make an application for the study to be considered for NIHR Clinical Research Network (CRN) support and inclusion in the NIHR Clinical Research Network (CRN) Portfolio? Please see information button for further details.

- ☐ Yes ☒ No

If yes, NHS permission for your study will be processed through the NIHR Coordinated System for gaining NHS Permission (NIHR CSP) and you must complete a NIHR Clinical Research Network (CRN) Portfolio Application Form immediately after completing this project filter and before completing and submitting other applications.

6. Do you plan to include any participants who are children?

- ☐ Yes ☒ No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

- ☐ Yes ☒ No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the NIGB Ethics and Confidentiality Committee to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or

who are offenders supervised by the probation service in England or Wales?

☐ Yes ☒ No

9. Is the study or any part of it being undertaken as an educational project?

☒ Yes ☐ No

Please describe briefly the involvement of the student(s):

The research is done as project towards the D.Psych (Counselling Psychology) degree.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

☒ Yes ☐ No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

☐ Yes ☒ No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

☐ Yes ☒ No

Integrated Research Application System
Application Form for Research involving qualitative methods only**Application to NHS/HSC Research Ethics Committee**

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting [Help](#).

Please define any terms or acronyms that might not be familiar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
The Impact of Diagnosis of AS on Women's Expectations of Relationships

Please complete these details after you have booked the REC application for review.

REC Name:

Cornwall and Plymouth Research Ethics Committee

REC Reference Number:

13/SW/0013

Submission date:

21/01/2013

PART A: Core study information**1. ADMINISTRATIVE DETAILS****A1. Full title of the research:**

The Impact of a Diagnosis of Asperger Syndrome on Women's Expectations of Intimate Relationships

A2-1. Educational projects

Name and contact details of student(s):

Student 1

	Title	Forename/Initials	Surname
	Ms	Elizabeth	Kock
Address	NSPC Ltd		
	Belsize Road		
	London		
Post Code	NW6 4BT		
E-mail	Lizziekock@gmail.com		
Telephone	07425179701		
Fax			

Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree:

D.Psych Counselling Psychology

Name of educational establishment:

New School of Psychotherapy and Counselling, Middlesex University

Name and contact details of academic supervisor(s):

Academic supervisor 1

	Title Forename/Initials Surname
	Dr Andre Strydom
Address	UCL Mental Health Sciences Unit Charles Bell House, 2nd Floor 67-73 Riding House Street
Post Code	W1W7EJ
E-mail	a.strydom@ucl.ac.za
Telephone	02076799308
Fax	

Academic supervisor 2

	Title Forename/Initials Surname
	Prof Digby Tantam
Address	NSPC Ltd Belsize Road London
Post Code	NW6 4BT
E-mail	digby.tantam@gmail.com
Telephone	02076240471
Fax	

Please state which academic supervisor(s) has responsibility for which student(s):

Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)	Academic supervisor(s)
------------	------------------------

Student 1 Ms Elizabeth Kock

- | |
|--|
| <input type="checkbox"/> Dr Andre Strydom |
| <input type="checkbox"/> Prof Digby Tantam |

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

- ☒ Student
- ☐ Academic supervisor
- ☐ Other

A3-1. Chief Investigator:

	Title Forename/Initials Surname
	Ms Elizabeth Kock
Post	Student
Qualifications	B.Psych, M.Phil.
Employer	Student
Work Address	NSPC Ltd
	Belsize Road
	London
Post Code	NW6 4BT
Work E-mail	Lizziekock@gmail.com
* Personal E-mail	
Work Telephone	07425179701
* Personal Telephone/Mobile	
Fax	

** This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.*

A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?

This contact will receive copies of all correspondence from REC and R&D reviewers that is sent to the CI.

	Title Forename/Initials Surname
	Dr L Ghali
Address	Department: School of Health and Social Sciences
	Middlesex University, The Burroughs
	Hendon, London
Post Code	NW44BT
E-mail	L.ghali@mdx.ac.za L. Ghali@mdx.ac.uk
Telephone	020841115727
Fax	

A5-1. Research reference numbers. Please give any relevant references for your study:

Applicant's/organisation's own reference number, e.g. R & D (if available):	N/A
Sponsor's/protocol number:	N/A
Protocol Version:	
Protocol Date:	
Funder's reference number:	N/A
Project website:	

Additional reference number(s):

Ref.Number	Description	Reference Number
------------	-------------	------------------

Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.

A5-2. Is this application linked to a previous study or another current application?

☐ Yes ☒ No

Please give brief details and reference numbers.

2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. *Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, this summary will be published on the website of the National Research Ethics Service following the ethical review.*

This research project will explore the experience of and desire for intimate relationships in some women with Asperger's Syndrome (AS) diagnosed in adulthood. It will address the impact, if any, that receiving the diagnosis has on women's intimate relationships. Literature on AS and existential literature will frame the study.

A6-2. Summary of main issues. *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

The study has been reviewed previously by another REC committee. Below are the comments of the committee and the current response to each of the comments
Committee Comment:

1. The Committee stated that the study is beneficial but the safety of the participant has not been addressed in the current design of the study.
2. The Committee expressed their concern that the participants in the study are extremely vulnerable and there is currently no support available if the participant becomes distressed during the interview. The Committee added that Ms Kock cannot act as both the researcher and treating counselling Psychologist. The Committee stated that there should be a clear referral mechanism in place.

Response

The potential risks and burden to participants are minimal.

All participants will be given an information sheet about the nature of the research, and the aims and objectives prior to commencement of the research. The interviewer will explain the procedure and the purpose of the study prior to obtaining written consent to participate. Participants will be made aware that they will be asked about intimate relationships.

Participants in the study will consent to their voluntary participation by signing the consent form. All participants will be able to decide independently if they want to participate or not, and can withdraw at any stage.

Participants' health will not be affected by them participating. In addition, participants will be told that they are not obliged to answer any questions with which they feel uncomfortable. Furthermore, the interview schedule will start with open, general questions, before progressing to more specific probes. Probes will only be based on the material participants offer. None of the questions will be intrusive - the participant will be able to decide how much or how little to reveal.

If the a participant does become distressed during the interview, she will be directed towards the service center which initially informed her of the study, i.e. Camden and Islington Foundation Trust, East London NHS Foundation Trust or Kingston Asperger Service. Participants will also have access to the local emergency or crisis teams.

If the participant discloses something that may require action, she will be directed towards the service center which initially informed her of the study, i.e. Camden and Islington Foundation Trust or East London NHS Foundation Trust or

Kingston Asperger Service. For example, safeguarding issues will be dealt with by these teams. Participants will be told that they are not obliged to answer any questions with which they feel uncomfortable. Participants are also free to end the interview at any time. They will be made aware that the researcher may have a duty to seek help if the interview reveals significant concerns.

Committee Comment:

3.The Committee were concerned that the aim and benefit of the study in unclear. The Committee stated that the detail and rational for the study should be clarified in the IRAS form.

Response

Intimate relationships are an important aspect of adult life. Although people with Asperger's Syndrome (AS) are said to be less "sociable" and less interested in close relationships than most other people, one of the main concerns that is often reported by adults with AS is the need for - and difficulties with - personal relationships. A formal diagnosis of AS may impact upon patients' (and their partners') expectations of intimate relationships. A formal diagnosis may have both positive and negative effects, and adjustment to the diagnosis may be an important determinant of longer term mental health and social outcomes. Clinicians need to be aware of patients' potential responses to a diagnosis and how it may impact upon their lives, in order to provide people with AS with the appropriate information and post-diagnosis counseling.

This research project will attempt to explore the experience of and the desire for intimate relationships in women who have been diagnosed with AS in adulthood. This aspect of the lives of women with AS has not yet been explored. The interview discussion will include themes regarding partner relationships. It is also anticipated that issues surrounding their family life will be discussed. In this regard the study will provoke an awareness of the need for possible interventions in terms of family and couples counseling.

Secondly, the current study aims to enable a better understanding of diagnosed persons' responses and adjustments to the diagnosis, which will likely have practical implications for clinicians involved in post-diagnostic counseling of people with AS. The study will thus be of interest to both the clinical and academic communities who work with people with AS.

Committee comment:

4.The Committee stated that the inclusion/exclusion criteria should be reconsidered for example, including anyone who has had a romantic relationship and excluding with a diagnosis of learning disability.

Response

As the population group is specific, purposive sampling is necessary to ensure that the participants are relevant to the research. Participating women will be approached via diagnostic clinics in London (one situated in Islington and the other in Newham), and Kingston.

An effort will be made to involve women from diverse ethnic backgrounds.

The sample will consist of women between the ages of 20 and 40.

All of the women will be in a intimate relationship or will have had a desire for such a relationship. Thus participating women must have gone on a minimum of one date.

The women will have recently (within the last five years) been formally diagnosed with AS and thus have had some time to adjust to the diagnosis.

To ensure that each of the participants has sufficient understanding of the English language and is capable of participation, it is required that the women have received either secondary or tertiary education in English, and have obtained a minimum of one GCSE.

Participants will not currently be seeing a doctor for a mental health problem (not counting AS).

Committee Comments regarding other considerations in resubmission:

Committee Comment

5.Explore all relationships as appose to focussing on romantic relationships

Response

The research is specific to intimate relationships. As stated in the aim of the project, little is known about women and their experience of intimate relationships. For the purpose of this study an intimate relationship will be defined a relationship as which includes a sexual relationship. Thus an intimate relationship as defined in this research will thus be distinct from friendship or family relations.

Committee Comment

6.Person information sheet to be on letter head

7.Information sheet to be consistent with NRES guidance

8.Add a statement to the Consent Form to consent to the audio record the interviews

Response

Attached are the revised changes

A6-3. Proportionate review of REC application *The initial project filter has identified that your study may be suitable for proportionate review by a REC sub-committee. Please consult the current guidance notes from NRES and indicate whether you wish to apply through the proportionate review service or, taking into account your answer to A6-2, you consider there are ethical issues that require consideration at a full REC meeting.*

☒ Yes - proportionate review ☐ No - review by full REC meeting

Further comments (optional):

Note: This question only applies to the REC application.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. Please tick all that apply:

- ☐ Case series/ case note review
- ☐ Case control
- ☐ Cohort observation
- ☐ Controlled trial without randomisation
- ☐ Cross-sectional study
- ☐ Database analysis
- ☐ Epidemiology
- ☐ Feasibility/ pilot study
- ☐ Laboratory study
- ☐ Metanalysis
- ☒ Qualitative research
- ☒ Questionnaire, interview or observation study
- ☐ Randomised controlled trial
- ☐ Other (please specify)

A10. What is the principal research question/objective? Please put this in language comprehensible to a lay person.

This is a qualitative research project that will explore the experience of intimate relationships of women who have been diagnosed with Asperger's Syndrome (AS) in adulthood. Intimate relationships are defined as sexual relationships, or relationships with the potential to become sexual relationships.

A11. What are the secondary research questions/objectives if applicable? Please put this in language comprehensible to a lay person.

In addition the study will explore what impact if any, receiving a formal diagnosis has had on participants' intimate relationships, or their perception of future relationships.

A12. What is the scientific justification for the research? Please put this in language comprehensible to a lay person.

Intimate relationships are an important aspect of adult life. Although people with Asperger's Syndrome (AS) are said to be less "sociable" and less interested in close relationships than most other people, one of the main concerns that is often reported by adults with AS is the need for - and difficulties with - personal relationships. A formal diagnosis of AS may impact upon patients' (and their partners') expectations of intimate relationships. A formal diagnosis may have both positive and negative effects, and adjustment to the diagnosis may be an important determinant of longer term mental health and social outcomes. Clinicians need to be aware of patients' potential responses to a diagnosis and how it may impact upon their lives, in order to provide people with AS with the appropriate information and post-diagnosis counseling.

This research project will attempt to explore the experience of and the desire for intimate relationships in women who have been diagnosed with AS in adulthood. This aspect of the lives of women with AS has not yet been explored. The interview discussion will include themes regarding partner relationships. It is also anticipated that issues surrounding their family life will be raised. In this regard the study will provoke an awareness of the need for possible interventions in terms of family and couples counseling.

Secondly, the current study aims to enable a better understanding of diagnosed persons' responses and adjustments to the diagnosis, which will likely have practical implications for clinicians involved in post-diagnostic counseling of people with AS. The study will thus be of interest to both the clinical and academic communities who work with people with AS.

A13. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

This study will utilize a qualitative research method and aim to provide an in-depth description of the experience of a number of women being diagnosed with AS in adulthood. Qualitative research is considered to be an appropriate approach when endeavouring to understand the experiences which are based on the perspectives of the participants, as this is a common thread in all forms of qualitative research (Elliot et al., 1999).

Participants in the present study will need to have a formal diagnosis of AS. To ensure this, participants will be invited from NHS clinics. These clinics will be based in London (Newham and Islington) and Kingston. The initial approach will be by clinicians within these services, who will pass information about the project to patients with a confirmed diagnosis. Potential participants will be asked to contact the researcher directly, or will consent to have their contact details passed to the researcher.

Initially the study will recruit twenty participants, however fewer may be required. While the study aims to explore intimate relationships, having a large sample size might compromise the depth of the analysis - although the sample size would need to allow for some comparison between participants. Initially the study will set out to recruit eight participants, and the population size will be reviewed after the analysis has been completed on the first eight narrative accounts.

Qualitative research is considered to be an appropriate approach when endeavouring to understand the experiences which are based on the perspectives of the participants, as this is a common thread in all forms of qualitative research (Elliot et al., 1999). Specifically the interpretative phenomenological analysis (IPA) approach will provide an opportunity to view the participants' 'lived experience' which is merged with a subjective and reflective interpretation, leading to insight into the participants' experience and perception (Reid et al., 2005). Lived experience is defined as 'to encompass the embodied, social-cultural and historically situated person who inhabits an intentionally interpreted and meaningfully lived world' (Eatough & Smith, 2008, p 181). The focus in phenomenology is not on the object but rather on the perception thereof (Smith et al., 2009).

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

- ☐ Design of the research
- ☐ Management of the research
- ☐ Undertaking the research
- ☐ Analysis of results
- ☒ Dissemination of findings
- ☐ None of the above

Give details of involvement, or if none please justify the absence of involvement.

Supervisors will ensure that the researcher receives training in how to conduct interviews in an appropriate manner and to accommodate the difficulties people with AS might exhibit. Interview discussion has been checked by professionals working directly with people with AS. We have support from the National Autistic Society (NAS), and the findings of the research which will be disseminated to organisations such as the NAS.

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS**A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).**

As the population group is specific, purposive sampling is necessary to ensure that the participants are relevant to the research. Participating women will be approached via diagnostic clinics in London (one situated in Islington and the other in Newham), and Kingston.

An effort will be made to involve women from diverse ethnic backgrounds.

The sample will consist of women between the ages of 20 and 40.

All of the women will be in a intimate relationship or have had experience of an intimate relationship (e.g. been on several "dates" with the same person).

The women will have recently (within the last five years) been formally diagnosed with AS and thus have had some time to adjust to the diagnosis.

To ensure that each of the participants has sufficient understanding of the English language and is capable of participation, it is required that the women have received either secondary or tertiary education in English, and have obtained a minimum of one GCSE.

Participants will not currently be seeing a doctor for a mental health problem (not counting AS).

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

Not being able to consent and lacking in capacity

Participants currently have an acute mental illness

RESEARCH PROCEDURES, RISKS AND BENEFITS**A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. These include seeking consent, interviews, non-clinical observations and use of questionnaires.**

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Consent	1		10-15min	Explaining study, written consent, at clinic or at home
Interview	2		60-90min	The student will conduct the interview. It will take place at diagnostic clinics or in participants' homes

A21. How long do you expect each participant to be in the study in total?

The process in total will take approximately 2 weeks from the information sheet being sent/ given to participants asking for involvement to the final contact.

The length of each interview will be in direct relation to the subjects' willingness to share information and experiences, and also the interviewer's success in evoking conversation from the subject. Sufficient time will be allowed for a rich and detailed response, but it is expected not to exceed 90 minutes.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

The potential risks and burden to participants are minimal.

All participants will be given an information sheet about the nature of the research, and the aims and objectives prior to commencement of the research. The interviewer will explain the procedure and the purpose of the study prior to obtaining written consent to participate. Participants will be made aware that they will be asked about intimate relationships, and how that is defined.

Participants in the study will consent to their voluntary participation by signing the consent form. All participants will be able to decide independently if they want to participate or not, and can withdraw at any stage.

Participants' health will not be affected by them participating. In addition, participants will be told that they are not obliged to answer any questions with which they feel uncomfortable. Furthermore, the interview schedule will start with open, general questions, before progressing to more specific probes. Probes will only be based on the material participants offer. None of the questions will be intrusive - the participant will be able to decide how much or how little to reveal.

If the participant becomes distressed during the interview, she will be directed towards the service center which initially informed her of the study, i.e. Camden and Islington Foundation Trust, East London NHS Foundation Trust or Kingston Asperger Service. Participants will also have access to the local emergency or crisis teams.

If the participant discloses something that may require action, she will be directed towards the service center which initially informed her of the study, i.e. Camden and Islington Foundation Trust or East London NHS Foundation Trust or Kingston Asperger Service. For example, safeguarding issues will be dealt with by these teams.

Participants will be told that they are not obliged to answer any questions with which they feel uncomfortable. Participants are also free to end the interview at any time. They will be made aware that the researcher may have a duty to seek help if the interview reveals significant concerns.

Participants will be able to withdraw from the study at any time up to one month after the interview.

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

☒ Yes ☐ No

If Yes, please give details of procedures in place to deal with these issues:

The research covers sensitive topics, but it is unlikely that participants will be distressed by the questions (as it will not be specific or intrusive), or that action will be required due to criminal or other disclosures.

The interview will be focused on three discussion areas:

1. Experience, desire or hopes for intimate relationships before the diagnosis
2. Experience, desires and hopes after the diagnosis
3. What impact if any has receiving a formal diagnosis had on their experience of intimate relationships

Participants will be told that they are not obliged to answer any questions with which they feel uncomfortable. Participants are also free to end the interview at any time. They will be made aware that the researcher may have a duty to seek help if the interview reveals significant concerns.

The procedure that will be followed if a participant does become distressed whilst conducting the interview has already been described. If the participant does become distressed during the interview, she will be directed towards the service center which initially informed her of the study, i.e. Camden and Islington Foundation Trust, East London NHS Foundation Trust or Kingston Asperger Service. Participants will also have access to the local emergency or crisis teams.

If the participant discloses something that may require action, she will be directed towards the service center which

initially informed her of the study, i.e. Camden and Islington Foundation Trust or East London NHS Foundation Trust or Kingston Asperger Service. For example, safeguarding issues will be dealt with by these teams.

A24. What is the potential for benefit to research participants?

Participants will get an opportunity to talk about their own experiences, which most people find enjoyable and useful.

A26. What are the potential risks for the researchers themselves? (if any)

The research will be conducted in a professional setting, or in participants homes if usual clinicians had deemed it to be safe, with access to help if required, therefore has low level of risk for the researcher.

In the instances where the interview is conducted within a home a risk assessment will be conducted and the necessary precautions will be followed.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used?*For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).*

Participants will primarily be recruited from diagnostic clinics in London (based in Newham, Islington) and Kingston. The initial approach will be by clinicians within these services, who will pass information about the project to patients with a confirmed diagnosis. Potential participants will be asked to contact the researcher directly, or will consent to have their contact details passed to the researcher.

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

☐ Yes ☒ No

Please give details below:

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

☐ Yes ☒ No

A29. How and by whom will potential participants first be approached?

See previous - for participants approached via clinics, the initial approach will be by clinicians.

A30-1. Will you obtain informed consent from or on behalf of research participants?

☒ Yes ☐ No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

Participants will be sent an information letter that explains the study.

Informed consent will be given by participants themselves. This will be done by signing a consent form.

If you are not obtaining consent, please explain why not.

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

☒ Yes ☐ No

A31. How long will you allow potential participants to decide whether or not to take part?

A minimum of 24 hours will pass between first receiving an information sheet, and being asked to consent.

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs?(e.g. translation, use of interpreters)

Participants will be fluent English speakers, though not necessarily first language speakers. They are not expected to have special communication needs but the researcher will be sensitive to the communication issues that is a feature of Asperger's Syndrome.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? Tick one option only.

- ☒ The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.
- ☐ The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.
- ☐ The participant would continue to be included in the study.
- ☐ Not applicable – informed consent will not be sought from any participants in this research.
- ☐ Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)?(Tick as appropriate)

- ☐ Access to medical records by those outside the direct healthcare team
- ☐ Electronic transfer by magnetic or optical media, email or computer networks
- ☐ Sharing of personal data with other organisations
- ☐ Export of personal data outside the EEA

- ☒ Use of personal addresses, postcodes, faxes, emails or telephone numbers
- ☒ Publication of direct quotations from respondents
- ☐ Publication of data that might allow identification of individuals
- ☒ Use of audio/visual recording devices
- ☒ Storage of personal data on any of the following:
 - ☐ Manual files including X-rays
 - ☐ NHS computers
 - ☐ Home or other personal computers
 - ☒ University computers
 - ☐ Private company computers
 - ☒ Laptop computers

Further details:

A38. How will you ensure the confidentiality of personal data? *Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.*

Each participant will be given a number which will represent them in the data. In this way no personal details of participants will need to be used in the analysis and reporting of the data. Access to original data is limited to the student and her supervisors.

A40. Who will have access to participants' personal data during the study? *Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.*

The researcher will have access to participants' personal data during the study. Participants will be made aware of this prior to participating in the research.

Storage and use of data after the end of the study

A43. How long will personal data be stored or accessed after the study has ended?

- ☐ Less than 3 months
- ☒ 3 – 6 months
- ☐ 6 – 12 months
- ☐ 12 months – 3 years
- ☐ Over 3 years

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

- ☐ Yes ☒ No

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

- ☐ Yes ☒ No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

☐ Yes ☒ No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

☒ Yes ☐ No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

A49-2. Will you seek permission from the research participants to inform their GP or other health/ care professional?

☒ Yes ☐ No

It should be made clear in the participant's information sheet if the GP/health professional will be informed.

PUBLICATION AND DISSEMINATION

A50. Will the research be registered on a public database?

☐ Yes ☒ No

Please give details, or justify if not registering the research.

Registration of research studies is encouraged wherever possible.

You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study? Tick as appropriate:

- ☒ Peer reviewed scientific journals
- ☒ Internal report
- ☒ Conference presentation
- ☐ Publication on website
- ☐ Other publication
- ☐ Submission to regulatory authorities
- ☐ Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators
- ☐ No plans to report or disseminate the results
- ☐ Other (please specify)

A53. Will you inform participants of the results?

☐ Yes ☒ No

Please give details of how you will inform participants or justify if not doing so.

The results of the study will be written up as part of thesis. The thesis will be publicly available. The findings will also be published in a scientific journal. Participants will be informed of this during the research.

5. Scientific and Statistical Review

A54. How has the scientific quality of the research been assessed? *Tick as appropriate:*

- ☒ Independent external review
- ☐ Review within a company
- ☐ Review within a multi-centre research group
- ☐ Review within the Chief Investigator's institution or host organisation
- ☐ Review within the research team
- ☒ Review by educational supervisor
- ☐ Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:

The research proposal has been reviewed by the supervisors, and approved by an examinations board.

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A59. What is the sample size for the research? *How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.*

Total UK sample size: 20

Total international sample size (including UK): 20

Total in European Economic Area:

Further details:

While the study aims to explore intimate relationships, having a large sample size might compromise the depth of the analysis - although the sample size would need to allow for some comparison between participants. Initially the study will set out to recruit up to 20 participants, and the population size will be reviewed after the analysis has been completed on the first eight narrative accounts.

A60. How was the sample size decided upon? *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

Previous studies noting the experience of people with AS use a relatively small population size. Howard et al., (2006) document the experience of one individual in their study; Muller et al., (2008) investigate the social experiences of eighteen individuals with AS while Punshon et al., (2008) document the experiences of ten participants.

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

The IPA approach will provide an opportunity to view the participants' 'lived experience' which is merged with a subjective and reflective interpretation, leading to insight into the participants' experience and perception (Reid et al., 2005). Lived experience is defined as 'to encompass the embodied, social-cultural and historically situated person who inhabits an intentionally interpreted and meaningfully lived world' (Eatough & Smith, 2008, p 181). The focus in phenomenology is not on the object but rather on the perception thereof (Smith et al., 2009). In utilizing IPA, interpretations can be made of meaning, cognition, affect and action (Reid et al., 2005).

An alternative consideration is Template Analysis (TA) which is another branch of phenomenological methodology. By employing TA the researcher makes use of a start-list which is relevant to the data that is being collected (Dickie,

2003). The themes that make up the start-list are derived from previous research (Langdridge, 2007). In the case of the present study where little research has been done regarding the topic, making use of template analysis could be problematic.

Reynolds (2003) uses both IPA and TA in a study concerning the meaning of an artistic occupation for women who live with chronic illness, and concludes that of the two methods IPA was more desirable as IPA resulted in a more in-depth understanding of the phenomena.

6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.

	Title Forename/Initials Surname
	Dr Deirdre O'Brady
Post	Consultant Psychiatrist for People with Learning Disabilities
Qualifications	
Employer	East London NHS Foundation Trust
Work Address	Unit 7/8 Stratford Office Village
	4 Romford Rd
	Stratford
Post Code	E15 4EA
Telephone	02082501507
Fax	
Mobile	
Work Email	deirdre.o'brady@newh ampct.nhs.uk

	Title Forename/Initials Surname
	Dr Maria Daves
Post	Counselling Psychologist
Qualifications	
Employer	Kingston Asperger syndrome Service
Work Address	Sherwood Centre
	Warren Road Kingston
Post Code	KT2 7HY
Telephone	020-8547-6641
Fax	
Mobile	
Work Email	Dr. Maria Daves

A64. Details of research sponsor(s)

A64-1. Sponsor

Lead Sponsor

Status: ☐ NHS or HSC care organisation
☒ Academic

Commercial status:

- ☐ Pharmaceutical industry
☐ Medical device industry
☐ Local Authority
☐ Other social care provider (including voluntary sector or private organisation)
☐ Other

If Other, please specify:

Contact person

Name of organisation Middlesex University
Given name Dr Lucy Ghali
Family name The Burroughs
Address Hendon
Town/city London
Post code NW4 4BT
Country UNITED KINGDOM
Telephone 02084115727
Fax
E-mail l.ghali@mdx.ac.uk

Is the sponsor based outside the UK?

☐ Yes ☒ No

Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.

A65. Has external funding for the research been secured?

- ☐ Funding secured from one or more funders
☐ External funding application to one or more funders in progress
☒ No application for external funding will be made

What type of research project is this?

- ☐ Standalone project
☐ Project that is part of a programme grant
☐ Project that is part of a Centre grant
☐ Project that is part of a fellowship/ personal award/ research training award
☒ Other

Other – please state:
Educational

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

☒ Yes ☐ No

If Yes, please give details of each rejected application:

Name of Research Ethics Committee or ethics authority: NRES Committee London - Bromley	
Decision and date taken:	unfavourable
Research ethics committee reference number:	12/LO/1118

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68. Give details of the lead NHS R&D contact for this research:

	Title Forename/Initials Surname
	Ms Angela Williams
Organisation	NoCLor (North Central London Research Consortium)
Address	3rd Floor Bedford House
	125 - 133 Camden High Street
	London
Post Code	NW1 7JR
Work Email	angela.williams9@nhs.net
Telephone	02033173765
Fax	
Mobile	

Details can be obtained from the NHS R&D Forum website: <http://www.rdforum.nhs.uk>

A69-1. How long do you expect the study to last in the UK?

Planned start date: 01/01/2013

Planned end date: 28/02/2014

Total duration:

Years: 1 Months: 1 Days: 27

A71-2. Where will the research take place? (Tick as appropriate)

- ☒ England
☐ Scotland
☐ Wales
☐ Northern Ireland
☐ Other countries in European Economic Area

Total UK sites in study

Does this trial involve countries outside the EU?

☐ Yes ☐ No

A72. What host organisations (NHS or other) in the UK will be responsible for the research sites? Please indicate the type of organisation by ticking the box and give approximate numbers of planned research sites:

- | | |
|--|---|
| <input checked="" type="checkbox"/> NHS organisations in England | 2 |
| <input type="checkbox"/> NHS organisations in Wales | |
| <input type="checkbox"/> NHS organisations in Scotland | |
| <input type="checkbox"/> HSC organisations in Northern Ireland | |

- ☐ GP practices in England
- ☐ GP practices in Wales
- ☐ GP practices in Scotland
- ☐ GP practices in Northern Ireland
- ☒ Social care organisations
- ☐ Phase 1 trial units
- ☐ Prison establishments
- ☐ Probation areas
- ☐ Independent hospitals
- ☐ Educational establishments
- ☐ Independent research units
- ☐ Other (give details)

1

Total UK sites in study:

3

A76. Insurance/ indemnity to meet potential legal liabilities

Note: in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? Please tick box(es) as applicable.

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

- ☐ NHS indemnity scheme will apply (NHS sponsors only)
- ☒ Other insurance or indemnity arrangements will apply (give details below)

Indemnity is provided by Middlesex University.

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? Please tick box(es) as applicable.

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

- ☐ NHS indemnity scheme will apply (protocol authors with NHS contracts only)
- ☒ Other insurance or indemnity arrangements will apply (give details below)

Middlesex University.

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS

sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

- ☒ NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)
☐ Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

NHS Indemnity will apply via Lead R&D for NHS patients

Please enclose a copy of relevant documents.

PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. For NHS sites, the host organisation is the Trust or Health Board. Where the research site is a primary care site, e.g. GP practice, please insert the host organisation (PCT or Health Board) in the Institution row and insert the research site (e.g. GP practice) in the Department row.

Research site		Investigator/ Collaborator/ Contact	
Institution name	Camden and Islington Foundation	Title	Dr
Department name	Islington Learning Disabilities	First name/ Initials	Andre
Street address	52D Drayton Park	Surname	Strydom
Town/city	London		
Post Code	N5 1NS		
Institution name	Newham PCT	Title	Dr
Department name	East London NHS Foundation Trust	First name/ Initials	Deirdre
Street address	7/8 Stratford Office Village	Surname	O'Brady
Town/city	Stratford		
Post Code	E15 4EA		
Institution name	Asperger Syndrome Service	Title	Dr
Department name	Asperger Syndrome Service	First name/ Initials	Maria
Street address	Sherwood Centre	Surname	Daves
Town/city	Warren Road Kingston		
Post Code	KT2 7HY		

PART D: Declarations**D1. Declaration by Chief Investigator**

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.
2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.
3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.
4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.
5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.
6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.
7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.
8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.
9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:
 - Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
 - May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
 - May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
 - Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.
11. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Contact point for publication*(Not applicable for R&D Forms)*

NRES would like to include a contact point with the published summary of the study for those wishing to seek further information. We would be grateful if you would indicate one of the contact points below.

- ☒ Chief Investigator
- ☐ Sponsor

- ☐ Study co-ordinator
☐ Student
☐ Other – please give details
☐ None

Access to application for training purposes *(Not applicable for R&D Forms)*

Optional – please tick as appropriate:

☐ I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

This section was signed electronically by Ms Lizzie Kock on 13/12/2012 17:28.

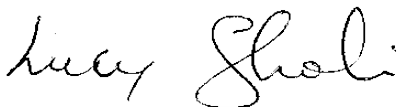
Job Title/Post: Student
Organisation: NSPC
Email: Lizziekock@gmail.com
Signature:
Print Name: Elizabeth Kock
Date: 11/12/2012 (dd/mm/yyyy)

D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co-sponsors by a representative of the lead sponsor named at A64-1.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.
2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.
3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.
4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.
5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.
6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.
7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.



Signature:

Print Name: L Ghali

Post: Principal Lecturer

Organisation: Middlesex University

Date: 11/12/2012 (dd/mm/yyyy)

D3. Declaration for student projects by academic supervisor(s)

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.
2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.
3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.
4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

Academic supervisor 1

This section was signed electronically by Dr Andre Strydom on 14/12/2012 19:23.

Job Title/Post: Senior Lecturer
Organisation: UCL
Email: a.strydom@ucl.ac.uk

Academic supervisor 2

This section was signed electronically by Professor Digby Tantam on 17/12/2012 13:49.

Job Title/Post: Deputy Principal
Organisation: NSPC Ltd
Email: digby@nspc.org.uk



254-256 Belsize Road
London NW6 4BT
+44 (0)207 624 0471
admin@nspc.org.uk
www.nspc.org.uk

Prof. Emmy van Deurzen – Principal
Prof. Digby Tantam – Deputy Principal

Elizabeth Kock
50 Inverness Mews
London
E16 2SP

14th June 2012

Dear Elizabeth

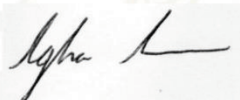
Re: Ethics Approval

Your application for ethical approval was reviewed by a member of the committee and has been given approval by chair's action under the following conditions.

Conditions

Ethics approval has been given on the understanding that you have approval only for research with participants not recruited through the NHS and on the understanding that you are applying for NHS research ethics approval separately

Yours sincerely

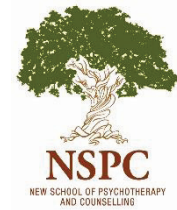
P.P. 

Prof Digby Tantam
Chair Ethics Committee
NSPC

www.nspc.org.uk

Registered Company No: 07239692, 27 Brocco Bank, Sheffield S11 8RQ. Directors: Emmy van Deurzen and Digby Tantam

Appendix 2 – Participant Information



Participant Information Sheet

Lizzie Kock
NSPC
258 Belsize Road
London
NW6 4BT
Ek437@live.mdx.ac.uk
Lizziekock@gmail.com
Tel: 074 251 79701

The Impact of a Diagnosis of Asperger Syndrome on Women's Expectations of Intimate Relationships

Supervisors: Prof Digby Tantam / Dr Andre Strydom

This research study is about women with Asperger's Syndrome (AS) and their intimate relationships. We would like to invite you to take part in this research. The study involves an interview with one person at a time. Before you decide, we would like you to understand why the research is being done and how you would be involved.– One of our team will go through the information sheet with you and answer any questions you have. This should take about 10-15 minutes.

What is the purpose of the research?

The aim of this study is to find out about the experience of, and hopes for intimate relationships.

We define an intimate relationship as a relationship that is also sexual. The experience of, and desire for intimate relationships in women with AS have not yet been explored. If you decide to take part, you will be asked about your experiences and expectations of these relationships. The research will aim to help professionals understand women with AS better.

Who are we looking for?

We are looking for women who

- have been diagnosed as having AS within the last five years,
- who have completed mainstream schooling in the UK
- have obtained at least one GCSE
- who are not currently seeing a doctor for a mental health problem (not counting AS)
- have been out on at least one date
- between the ages of twenty and forty.

E.Kock Version 3 23.01.2013 - 13/SW/0013



Do you have to take part?

No.

Whether or not you take part will not affect any treatment or help that you are getting at the moment. On the day of the interview, a copy of this information sheet will be given to you again to ensure that you are aware of what the research entails. In addition, you will be asked to sign a consent form before taking part in the research.

You do not have to take part if you do not want to. If you decide to take part you may stop the interview at any time without giving a reason. Once the interview is complete, you will still have up to a month to withdraw from the study if that is what you want to do. The help and treatment you currently receive will not be affected if you withdraw from the study.

What will happen if you take part?

If you decide to take part in the research, I will arrange to meet you so that I can ask you for some background information about yourself, and then conduct an interview with you. I will ask you about dating (going out with a person you would like to have an intimate relationship with), relationships you have and whether or not this has changed since you were diagnosed.

This interview will take place at:

Camden and Islington Foundation NHS Trust
52D Drayton Park
London
N5 1NS

Or
East London NHS Foundation Trust
7/8 Stratford Office Village
Stratford
E15 4EA



Or
258 Belsize Road
London
NW6 4BT

Or
Asperger Syndrome Service
Sherwood Centre
Warren Road
Kingston
KT2 7HY

If it is easier for you, I can come to your home and conduct the interview there. If you want to, you can ask someone to come with you to the interview.

The interview is not expected to last longer than 90 minutes. You may stop the interview at any time you want to.

I will be recording what we say on an audio recorder, and will make sure that this recording is kept safe until it has been typed up. When it is typed up your name and other identifiable details will be changed.

Once we have finished the interview, there will be time to think about the interview and what it was like for you to talk about your experiences. You may ask any questions you might have surrounding the study.

What are the possible advantages and disadvantages of participating?

Some people find it useful to talk about their experiences with someone who is good at listening. There is no direct benefit to you, but your involvement may help us to better understand the experience of intimate relationships in women with AS.

There are no physical risks, but if you should become upset during the interview for any reason, you can ask to stop without giving a reason. With your permission I will inform the NHS trust who will give you the necessary support.

E.Kock Version 3 23.01.2013 - 13/SW/0013



Will your taking part in the study be kept confidential?

Yes. No information received will be passed on to any of your friends, family or other professional staff e.g. nurses or doctors. Only my Supervisors and I will know who you are.

Your GP/principal health care professional will be informed of your participation in the study unless you do not want him/her to know. If your GP/principal health care professional is informed, he/she will be told that you participated in the study but not what you said during the interview.

Information gathered from this study may be presented in scientific meetings or scientific journals, but I will not use your name or any identifying information about you. Your identity will be kept private, and names and any other recognisable information will be changed. I will want to use some of your words and quote you directly. I will ask you on the day of the interview if you are comfortable with this, and if you are not, I will not use your exact words.

The initial recorded interview and the written account you will be asked to provide, will be kept for 5 years after which it will be destroyed.

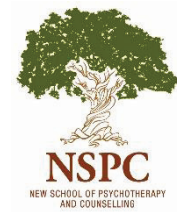
When will confidentiality will be broken?

If you are at serious risk of harming yourself or others; or there are concerns for the neglect or abuse of children, then we will have to share your information with agencies, This may be without your permission. If this happens we would discuss it with you first.

What happens after the interview?

The recording made during the interview will be transcribed and studied further. We hope to publish the material in an academic journal. You will not be identifiable as all recognizable details will be changed.

As mentioned before, once the interview is complete you will still have up to a month to withdraw from the study if that is what you want to do. In this case, all the details I have of you will be removed from the study.



Complaints

If you have a concern about any aspect of this study, you should ask to speak to the Researchers who will do their best to answer your questions (contact details: email: Lizziekock@gmail.com; and telephone no. 07425179701). If you remain unhappy and wish to complain formally, you can follow the NHS Complaints Procedure. Details of this can be retrieved from:
<http://www.nhs.uk/choiceintheNHS/Rightsandpledges/complaints/Pages/NHScomplaints.aspx>

Who has reviewed the study?

All proposals for research using human participants are reviewed by an Ethics Committee before proceeding. This study has been reviewed and approved by the New School of Psychotherapy and Counselling Ethics Committee. Furthermore, all research in the NHS is looked at by an independent group of people called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by South West Research Ethics Committee.

If you do decide to take part in the study, please contact me directly to discuss a suitable time and date for the interview.

Thank you for reading this information sheet.

Lizzie Kock

.....
Date

E.Kock Version 3 23.01.2013 - 13/SW/0013

Appendix 3 – Consent form

Camden and Islington
NHS Foundation Trust



Centre Number:

Study Number:

Patient Identification Number for this trial:

CONSENT FORM

The Impact of a Diagnosis of Asperger Syndrome on Women's Expectations of Intimate Relationships

Researcher: Lizzie Kock

Supervisor: Prof Digby Tantam/ Dr Andre. Strydom

Please initial boxes and sign overleaf.

1. I confirm that I have read and understand the information sheet dated.....(version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

. ☐

2. I understand that my participation is voluntary. I also understand that I am free to withdraw at any time up to a month from the date of the interview without giving any reason and without my medical care or legal rights being affected.

☐

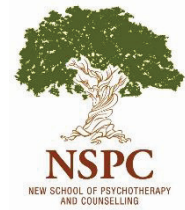
3. I further understand that the data I provide may be used for analysis and subsequent publication.

☐

4. I consent to be quoted and understand that my quotes will be anatomised.

☐

E.Kock 23.01.2012 Version 3 - Rec Ref: 13/SW/0013



5. I consent to the interview being audio recorded.

☐

6. I consent that my GP/health care professional is informed of my participation in the above study.

☐

7. I understand that relevant sections of my [medical] notes and data collected during the study, may be looked at by individuals from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

☐

8. I agree to take part in the above study.

☐

.....
Name of Participant Date Signature

.....
Name of interviewer Date Signature

Appendix 4 – Interview schedule



Interview Schedule

Lizzie Kock
New School of Psychotherapy and Counselling (NSPC),
258 Belsize Road,
London
NW6 4BT
Email: Lizziekock@gmail.com
Tel: 07425179701

The Impact of a Diagnosis of Asperger Syndrome on Women's Expectations of Intimate Relationships

Lizzie Kock

Supervisors: Prof Digby Tantam and Dr Andre Strydom

Background Information

Name:

Trust:

Participant nr:

Date of Birth:

The date and month of when formal diagnosis was received:

Brief Synopsis of Research

This is a qualitative research project that will explore the experience of intimate relationships of women who have been diagnosed with Asperger's Syndrome (AS) in adulthood.

E.Kock 05/08/12 - Version 2



Definition of Intimate Relationships

Intimate relationships in this research are defined as sexual relationships, or relationships with the potential to become sexual relationships. These types of relationship might be with a boyfriend or girlfriend. It might also be with someone you go or have gone on date/s with.

Discussion

- Many women would like to have an intimate relationship - have a boyfriend/girlfriend. Some might want to get married. Why do you think they might want this?
- What might be difficult about intimate relationships?
- What might be good/positive about intimate relationships?
- What would an ideal relationship be?
- What has been your experience of intimate relationships?
- What do you find difficult/challenging about intimate relationships - is there certain aspects of intimate relationships that you find more difficult?
- What do you find good/positive about intimate relationships?
- Has receiving the diagnosis of Asperger's Syndrome changed the way you feel about intimate relationships? In what way do you feel different?
- Have some aspects of intimate relationships become more difficult or challenging since the diagnosis?
- Have some aspects of intimate relationships become easier or better since receiving the diagnosis?
- How do you feel about relationships since the diagnosis?

E.Kock 05/08/12 - Version 2



Thank you for taking part in this research project. It forms part of my Professional Doctorate (D.Psych) in Existential Psychotherapy and Counselling. The purpose of this research is to explore the impact of receiving a diagnosis of Asperger's Syndrome has on some women's expectations of intimate relationships. The next step from the interview is to transcribe and give further consider to the information you gave us.

This study has been ethically approved by the NHS Ethics Committee. If you are interested in reading more about this research or anything related to it, or if you have concerns or issues arising from this research or interview, please feel free to contact me or the NHS trust. As mentioned in the information sheet, you can withdraw from the study up to a month from the interview day without giving any explanation. Withdrawing will not affect any care that you are receiving.

I am happy to answer any questions or to respond to any immediate concerns at the end of our interview.

Thank you again for your participation.

Kind regards

Lizzie Kock

Appendix 5 – Transcribed interview

- LIZZIE: Could you tell me a little bit of your experience of romantic relationships?
- CARA: Um... I don't know where to start really...
- LIZZIE: That's okay... are you in a relationship at the moment?
- CARA: Hopefully! ...just because of... like I said [to him] I needed a week just to kind of clear my head... but said that I still wanted a relationship... but somehow my behaviour was making me a bit unhappy. So yeah, I have been seeing someone for about 6 - 7 weeks.
- I guess since the diagnosis it is the first kind of dating stuff... the first seeing somebody since then - and he knew about the Asperger's diagnosis before, which was a hell of a help actually.
- LIZZIE: How so?
- CARA: Because I feel I didn't have to 'come out' (laugh) as before and I had at some point have to say 'oh, by the way...' or I had to act in a way that was somehow suppressed... don't give the game away, don't give the game away... of not having to kind of feel... Like I have to try and maintain or act or assess what I'm doing... like question what I am doing... kind of like try and make them not think you are weird. Actually, before I knew I had Asperger's... this is kind of complex... before I knew I had Asperger's... so I went on a couple of... I am delivering this jumbled...
- LIZZIE: This is very helpful to me...
- CARA: I joined a dating club because I wasn't going to be in a situation where I would not be meeting people and so I went on...
- LIZZIE: Was this pre- or post-diagnosis?
- CARA: This is post diagnosis... so there were two or three dates with people from there. I did not want to give the game away, I felt I almost kind of had to portray, or kind of not... not do anything that was going to be too odd so as to not freak them, and also not know what might actually and obviously freak them. You're kind of working out what would, what... for want of a better word, normal is.
- LIZZIE: Just to check if I understand correctly, the concern is not only about giving the game away, but also working out what the game is?
- CARA: Yes, but also I suppose it's kind of not... fear of being found out before you were ready to tell them. And suppose I would want to tell them like this... well, once they really knew me and once they kind of... I would want to tell them: 'please, what you see is pretty me, please don't be freaked out by this, I have some things that I will do that might seem odd to you and silly things which would upset me'. With the guy I see now, because he already knew that and he actually works as a support worker for people with Autism, I feel he is going to have some idea and also not be freaked out by

having some kind of diagnosis and not quite knowing how some of this would manifest.

LIZZIE: Do you think people are freaked out by having a friend or a partner with Autism?

CARA: I don't know... I think it depends... if you find the right one, probably not! (laughter) But I think somebody might kind of... could be... I never kind of told anybody and have them freak out.

But I know that sometimes I am more kind of blunt or open with people than what they expect me to be. I think people find that a bit, a bit strange... (long pause)

LIZZIE: And having had a diagnosis - does that help at all?

CARA: It helps... generally in an intimate relationship. I think in some ways there hasn't been... because I have been told I have mental health problems. I thought difficulties of Asperger's were just, well just me being crazy, I thought it was just me being crazy! (laughter) It probably has actually helped me to come to terms with myself a bit more and I think in a non-direct way, that will help me in terms of relationships because you feel a bit more easy about yourself or you come to terms with aspects of understanding yourself and helps your doubts and its hugely helpful in putting some aspects of past experiences into perspective, or various things that happened. I felt more cohesive and I find that has probably helped me feel a little more at ease with myself than I had done before and I think that that's obviously not a direct thing but I can see how that should in theory and in practice, make life in relationships easier.

LIZZIE: It sounds like it gave you some confidence. Is that the right word?

CARA: Confidence... yeah... acceptance would probably be the right word. Some sort of self-acceptance. Because I suppose I've been thinking of myself as lacking and wanting to improve loads of aspects of myself. Thinking I just have to... stop being such a wimp about noises and just get on with it.

But now I can say hang on, you might not be able to. You might just need to structure your life in a way that you can avoid some of the challenges rather than thinking I have to man up to them. And not constantly seeing yourself as deficient in some way. That alone helps.

LIZZIE: I wonder how that will apply to interactions and specifically intimate relationships.

CARA: I think probably the ways in which Asperger's affect you particularly is... So I have not had a lot of romantic experiences. I guess... I think that's purely because I am shit at noticing it when somebody is interested physically... like body language wise. So I will ask my friends. I will say to them: Do you guys sometimes look at me and I don't notice it? So they say 'yeah!' Although I can tell when somebody talks to me, to some extent. Although I am a bit slow on the uptake... like walking away I was thinking he was actually trying to chat me up, maybe... but in terms of physically, I think if somebody was eyeing me up, I would know... occasionally. It's not the sort

of thing I am good at... which I kind of contribute to... I kind of lack of experience so I think it affect me in that way. (long silence) Some missed opportunities I guess.

LIZZIE: You seem thoughtful when you mention missed opportunities. Are romantic relationships something that is important to you?

CARA: It's not a kind of be all for me. It's... so part of joining a dating site thing - it's part of thinking well, before I dismiss this thing that perhaps you didn't actually want this... because you're quite happy being on your own and if this happens, it happens.

Because I think it's hard to differentiate between your own wants and what you feel you are and social expectations of you... (silence) ... particularly social expectations...

LIZZIE: Social expectations?

CARA: Oh, you grow up in an environment where, I mean my parents aren't like: 'when are you getting married?' Or anything like that. They are generally kind of... a general social thing is that it's the norm to settle down and have relationships, that sort of thing. But it's part and parcel of social existence I guess, and what people's expectations are of you. So, I thought I actually maybe... so I hadn't actually seen somebody for over three years at that point.

LIZZIE: Were you mindful of these expectations?

CARA: Well, I suppose I thought before I dismiss this relationship thing completely I better see if I like it. So yeah, then I went on two or three dates. The guy I am seeing at the moment I actually met nearly five years ago... a friend of a friend...

LIZZIE: Oh?

CARA: Through a friend, so we knew of each other's existence - so I went over to him on a date with friends in the Peaks and we went back to his house and we started talking and sort of hit it off. We tentatively played this game of do we like each other. The game resolved itself about six weeks ago. We said: 'yeah, I like you, you like me...' He sent a text saying he liked me and let's hang out. I sent one back. I replied slightly, or actually bluntly asking: 'in what way do you like me?' (laughter). You must think it is not very... I don't know...

LIZZIE: It sounds very gutsy! (laughter)

CARA: (laughter)... Is it stupidity or guts!? - I don't know! Mom said: 'that's a bit blunt, Cathy!' But at that point I was reasonably sure that he was really into me. Well, reasonably sure... yes, definitely reasonably!

LIZZIE: How did you know?

CARA: Well, we had been talking to each other a lot. We'd been talking a lot on Facebook and he would comment on things that I'd got or do. He did this more so than other people and probably it seemed a little kind of... he certainly wanted to get know me a little better. He would say: 'would you

want to go for a drink or chat, I certainly would like to see you sometime.' And then I would be thinking: is he asking me out or is he doing this deliberately so that it could be interpreted in two ways (laughing) exactly like I would do things to test things and not stick my neck out to far... you know... (laughter)

LIZZIE: Play it really cool?

CARA: Playing it cool! (laughter)... yeah, it's kind of this could be read both ways. Then we went for a weekend at my friend's house. I realised when we were talking we were doing the mirroring thing... you know... the kind of mirroring thing that people do. I read about it in magazines and see it on TV - whether somebody likes you or whatever. Or I noticed we had our hands in the same position cos I was actually looking for a sign and it was interesting that we were both kind of copying each other's physical positions.

LIZZIE: It is the kind of thing that is often in mags like Cosmopolitan magazine...

CARA: Yes, yes exactly! And then thinking is this indicative of simply getting along well, I suppose. Also just looking each other in the eye at one point and actually thinking are you staring at me... I am staring at you as well!!

LIZZIE: What was that like?

CARA: I presume there must have been some sort of spark... or it a staring contest? (laughing)

LIZZIE: I am wondering - because we spoke a little bit - about having some difficulty in picking up other's romantic intentions...

CARA: I think certainly in conversation with somebody that would be easier than somebody looking at you across the room, that sort of thing...When you're having a conversation with somebody - that would be easier for me to pick up as opposed to looking at you across the room. I know I am better. I am reasonable one-on-one or two other people, maximum three other people - after that I am confused. I just kind of pull back and don't know what's going on and find it hard to follow.

LIZZIE: How do you find it with your partner?

CARA: We talked about things we have in common, common interests...Wits easier for me to talk about things rather than just kind of... I don't know... chat.

LIZZIE: Yeah?

CARA: I guess also because we know a little bit about each other. Well, I certainly know a little about him because all of my friends - we have a mutual friend who is quite close to both of us so I kind of heard a lot about him. [I] kind of thought he was really interesting. I don't know what he heard about me... (giggle) but he must have heard about this Asperger's thing... Fiona must have told him.

LIZZIE: Did you ever ask him if he knew about it?

CARA: I mentioned it to him... he already knew.

LIZZIE: What was that like?

CARA: So I am guessing that it was intuition I guess that he knew (long silence). Right, I don't thinking it's massively obvious unless you know me or if you catch me at a very bad time. If you catch me when I am stressed you might figure it out. I think you might otherwise think I am a bit awkward and bit odd... (giggle)

LIZZIE: This reminds me a bit about what you said earlier about 'coming out'. I wonder how you felt at these times?

CARA: It is just reassuring that he knows this already and he's not going to be freaked by it... knowing that I am kind of (long silence)...I suppose it is like buying a house or a car - you want to know what the problems are with it before you choose to make a decision about it rather than discovering something later along the line. Also, I have this tendency to be like... give away a lot more than I need to give away... like I say about myself.

LIZZIE: Could you give an example?

CARA: Well, I confess to things... I'll immediately confess to things... not to be accused of things but for example, I would... I probably feel I did not need to tell him but I ought to tell him, or just... I am trying to think of an example because I get told I do this... uhm... I am trying to thinking of a good example right now...I tend to blur things out. If I've done something and thought somebody might disapprove of it, I probably would not keep it a secret, I probably would tell them - I just have this overwhelming compulsion to say so.

LIZZIE: Is this similar to buying the car?

CARA: Yeah... because I'm not kind of... it gets me into trouble because I'm not kind of like... things could probably been soothed or ignored... I would say something which kind of then would have to be kind of repaired - because I'm actually sorry - that kind of thing...Keeping something from somebody I feel is very difficult to do. So it's not kind of... I suppose I feel they should know. So I don't kind of keep things - I feel I kind of need to tell everybody about things for no particular reason, like... I have half a loaf bread left in the bread bin... or whatever...You don't have to know that but I feel somebody needs to know. Or I feel bad, maybe it's all my own need for them to know things are just... I don't know... I need to say... I don't know. I suppose I feel burden of carrying it around makes me feel bad, but also because I feel like I am hiding something from somebody and I hate doing that... I really don't like doing that.

LIZZIE: What about the diagnosis... how do you feel about telling people about it?

CARA: The Asperger's thing... being able to talk about it with the guy I am seeing at the moment is helpful because I feel I can say, I don't like this because I don't want to do this, or that might be difficult, or this. It gives me and him a clear reason...Actually I don't tell him everything because some stuff I do... I find embarrassing. For say example, if I got really stressed about something and was trying to throw myself against the ground to get some sort of sensory feel, some kind of pressure, or kind of pressure, or kind of impact that would calm me. Or kind of my parents need to hold me, not to restrain me because I am kicking off, but would hold me very tightly to feel

calm. And I did not say all that because it would sound possibly scary or unattractive...

LIZZIE: That must be quite hard - having the need but feeling embarrassed by it.

CARA: This is something that I don't know if it carries on. Exposing somebody to those aspects of myself ... it is going to be tricky.

LIZZIE: Do you worry about it?

CARA: I have not done as yet. I mean, the things I worry about are cohabitating with somebody I find very difficult. So I'd rather see him at my place than at his place... so that I could retreat to my own... if I wanted to. The same could be said for having children. Do I want children? Well, I am not sure I can cope with them. Also maintaining two separate households is much more difficult - you know, also having all that kind of space to myself and the noise of children... I think about it often.

LIZZIE: Sounds like an important consideration.

CARA: But I have never been in a relationship with somebody long enough to discuss that. My take would be well, if I accidentally would get pregnant and it wasn't through rape or something horrible or that I would die at birth, I would probably keep the child, but it's not something I actually want because I am not sure what kind of parent I'd be. I would want to be a good parent, but I find them impossible... (giggle)

LIZZIE: Do you want to be a parent?

CARA: I don't not want to be a parent, though I don't feel any particularly strong urge to be a parent. I mean, I like children but I am not sure I can cope with them. Or kind of, rather I like children. I also like children you can hand back to somebody else. That kind of thing. If I had brothers and sisters, I'd quite like them to have children so I can look after them, whatever the case may be. But I prefer pets and animals - I like cats... also dogs... rats... that kind of thing. I guess if I were in a relationship long enough, I would have to discuss that. But coming back to aspects of AS - when you are seeing somebody about once a week and he lives about 40 miles from here, you can kind of present a sanitised version of yourself, you could rain it in. I find the social interaction tiring. One-on-one is not quite so bad, but I rest afterwards.

LIZZIE: What does rest mean to you?

CARA: I'd probably go to bed...

LIZZIE: Okay, so really resting?

CARA: Really resting, yes. But also just going on the computer and really not talking to people for a couple of hours. Sometimes actually, yes, it could be that I go to bed. I had a kind of an instance where a friend often, yes she came around and we did some fruit picking and we were doing some talking about the mutual friend who I was telling you about. It was really nice. But by lunch time the next day - her parents were, well her parents were here as well - and I was getting quite tired and becoming a bit snappy and was

thinking in my head: Mom could you put Fiona away now please (laughter)... and I actually went to bed and had a rest. It was bad because I had snapped at my dad about it... I was just really kind of being fed-up with being around people you know... break the routine so I was... I went to bed for a bit (laughter again). But she didn't seem to be too perturbed by it. It has been brought up again - I think she found it pretty amusing...

LIZZIE: Sounds like you are good friends! (laughter again) In a way that's what I am hearing with regard to intimate relationships as well - it's something you want, but it's also something that really tires you.

CARA: Yes, so it is kind of... kind of... it hasn't actually happened so far really, but I have warned him: If I want to be on my own, if I don't want to talk, it's not a comment on you - it's a comment on me needing rest... away from people but because it may be misinterpreted as not wanting to be around or a personal comment on him - and it is not. Or, if it was, I would let him know. It's kind of... it's all a bit much to handle.

LIZZIE: Were you aware of this before the diagnosis as well or did the formal diagnosis help?

CARA: Yes! Really, I could be difficult and snappy at times or get distressed or very tired really, if I don't have a break from people. Yeah, so it is a sort of self-awareness that came from it. Yeah, I think I was aware that I am someone who would spend quite a lot of time on my own... quite a lot actually. So I had known already that I did not like buzzy social situations. Definitely liked having time to myself... wanting to shut myself away for a bit. So yeah...

LIZZIE: What were romantic relationships like before you had the diagnosis?

CARA: I had dated people... probably the longest was a long distance one which lasted three or four months with a guy who may have been on the Autistic spectrum himself. It has been suggested to him but as far as I know he hasn't had a formal diagnosis. And that was the longest one and we got on rather well although he had difficulties of his own being very idiosyncratic person. It was a real one off. Lovely in some ways and an absolute pain in the backside in others. So we went out for four months in 2009 and stayed friends afterwards for quite a while. Maybe there probably was a kind of mutual accommodation for each other's oddities... I don't know. I think one thing I did think - I sometimes would go out with other people, because there was no reason not to, and they would ask and I for one was not particularly keen but given some time, you might... you know... if you give it a go you might find that you like him.

LIZZIE: I wonder if the social expectation you spoke about earlier, also played a role?

CARA: Possibly yes! Yeah, I think that after some time you feel that you perhaps ought to because you can't think of a significant excuse in the moment why you should not... I think? I think certainly when I was a teenager, early 20's, I had trouble working out whether someone was being friendly or romantically interested. And that I think is why I probably spent six months going on one year moping over this one guy who was interested in being friends with me but not in a romantic relationship. I don't think... I think I

was very confused by the whole thing and a complete pain in the ass to him - I did not stalk him exactly but I kind of moped around him hopefully, which is quite sad and pathetic don't you think?

LIZZIE: I don't think it is sad or pathetic, it sounds confusing and hopeful.

CARA: I think he was interested in being friends but I couldn't tell the difference or I think I probably still don't. You know, people flirt with you without having romantic intentions towards you and that I think is....And also, people's feeling towards you can change i.e. either people might be interested in you and cool off you quite quickly whereas for me it's kind of once you like somebody, you like somebody... so for me it's not kind of fickle... it's not that kind... if you like somebody once, you must always like them - which I don't think actually is the case. It's actually quite hard for me to remember - other people may not be that consistent or flirt with you without being interested...I don't know when to tell the difference when somebody is flirting or just showing a friendly interest in you. And I don't know how to be honest if I still could. Obviously you think something is okay if they touch you, but then some people are more touchy than other people - so it's hard to tell. Maybe it's something that everybody struggles with actually, that it is not an Asperger's kind of experience, I mean that kind of...But I suppose not being able to work out if somebody else might be reading the situation different to you, is something I could think about quite theoretically now. So I can say to you yes, even I think this is going on but that does not necessarily mean that they have the same interpretation of the same situation that I do. But I think actually in that situation I would find it very hard to have the kind of theory of mind to have that awareness.

LIZZIE: So there is a difference between knowing in theory - but it is different when you are in the situation?

CARA: I don't know in the situation. I can theoretically accept that something different is going on to what I think is going on - but by working out and by keeping in mind my interpretations, is something... I can think it, but not carry it out in practice.

LIZZIE: That reminds me of what you said about the guy you dated in your early 20's.

CARA: I did not date him... That's the thing: I moped over him even though we did not go out on any dates. I thought he was interested in me and I think I found it very difficult to work out that he wouldn't be, or realise that someday... he would actually change his mind and just give in. I thought he must fancy me in some way and he's just for some reason not showing it. Nothing sexually actually happened between us - but also because I went to university and never dated anybody. I kissed somebody once for a dare but that was my limit of knowledge and so befriended... no that sounds creepy... but I suppose friendship with this guy. It did not work out then but in retrospect he was actually just being friendly towards me. Or maybe it's the kind of borderline flirting which is sort of... they wave the cheque but don't want to cash it! You know, so when working it out, people flirt for the sake of it rather than as a kind of pre cursor - and to see the sincere

intention is kind of difficult for me. I was going to say to you that I get that some people will flirt with no intent. But why would they want to do that?

LIZZIE: You seem to think very carefully about the interactions...

CARA: Yeah, I suppose it would be an understatement to say I tend towards introspection... (laughing)

LIZZIE: You do seem very reflective...

CARA: Thanks... so yeah, I didn't really have any experience of romantic relationships until... I went out with somebody in my first year at university for some time, I went on a couple of dates but I wonder if these count...

LIZZIE: What would make it count?

CARA: It's very difficult because I don't think there is a clear definition of them at all. For example, I wouldn't say it's just about sexual desire... because romance can be separated from sexual desire. But then some people can separate it and some people can't...

LIZZIE: What about for you?

CARA: I think, go through the motions where you feel soulless and horrible, but I suspect I probably could, but I wouldn't want to because I think if I feel anything, I would feel completely mechanistic and I wouldn't want that - it would be a kind of half way thing - because I do think some people could go out and get off with somebody without feeling any romantic involvement but still feel having got some pleasure or enjoyment out of it, or some kind of buzz from it. I don't think I really could... I probably could but not feel anything at all... but then I think I could do this with as much enthusiasm as... cleaning my teeth! But if I had a romantic feeling for somebody, then yeah, or liking them. If I fancy feeling, or like for somebody or an attraction to somebody, then it becomes something more. So...

LIZZIE: So it's liking this person and attraction...

CARA: So it's liking this person. I mean, I guess kind of people's relationships tend to.... I guess something I can accept abstractly and approve of it from a kind of moral philosophical point of view - that people's relationships don't have to follow a particular pattern you know, everybody's kind of unique in everything, which I could kind of accept theoretically. And then I can think yes, people should not all have to have the same relationships as each other. But I think at the same time, I kind of feel... like I want a script or directions as to what one is meant to do... which is... actually going back to the PhD thing which I found very difficult because I knew there were not concrete expectations and there was a vagueness about it... and it gets so with romantic relationships... I think what a romantic relationship is, is very vague and something maybe individual people have individual conceptions of. Obviously there is a sort of broad area as to what falls into it... so that there is a very broad... and within that there is grey and people don't necessarily have the same view. I think that's what you would find if you did an in depth survey on it. I don't know if that makes sense...

LIZZIE: No, it makes sense. I suppose the boundary for what can be called romantic relationships is really vast...

CARA: Really vast... it's really very blurred...

LIZZIE: And that could be hard...

CARA: That could be hard... I accept that it is. In some ways I feel I need guidelines how I go about conducting a relationship with somebody...

LIZZIE: And how do you then, if there is no rule book - how do you go about conducting...

CARA: Exactly! This is what I find quite difficult, and I guess I feel a lot of social interaction that although that is as you say, there are no rules, there is no rule book or whatever, you quite quickly or unpleasantly find that you've actually breached one of the rules that actually didn't exist!

LIZZIE: Yeah... and has this happened to you that you breached the rules?

CARA: In intimate relationships - mmm, no not massively. But it is something I feel nervous about. And I guess that now that I've been seeing this guy for longer and I feel a bit... well, I know how to go on dates with people... well, to some extent I kind of know I feel comfortable but I don't know where to go from here and probably just do carrying on going on dates with people and feel comfortable doing that and find some activity to do together - that sounds so dodgy - other activities as well! (laughter)

LIZZIE: I don't think our smiles are captured on the recorder- what would these activities include...

CARA: ...including sexual activities but not limited to...!

LIZZIE: Okay...

CARA: So we've gone on walks, we've gone to art galleries, we've gone to gigs - those kind of things where you think there is some point to the event and have some kind of dating activity. So I find that easier to continue but I'm not so sure of where else you go or what people do - is that what people actually do... go to things together or decide to do something for a kind of long period of time until they decide they should break up or shack up together or...

LIZZIE: ...sounds like this is a minefield. How do you do that...

CARA: How do you do that? Yeah, because it seems the silliest thing. To most people it seems non-worry, they don't even question what they're doing or meant to be doing - it just feels right. So I am not sure if this is a sort of Asperger's thing or ... oh, my God, are you really, really, really self-conscious? But I think it is that because there is a desire for a kind of certainty or a pattern of how you are meant to carry on - a sort of protocol about romantic relationships with people. People... kind of presume that other people know... perhaps they don't know, you know. I may think, like talking again to Adrian, there are no rules; you make your own rules - which is nice in some ways because one feels you don't have to conform to anything. On the other hand, it's like please, give me your list of

expectations and I will try to conform to these, thank you! Not so much as to serve you but kind of... out of - I want to know what to do, please! I don't know if it's that an issue for other people... I haven't talked about it with my friends...actually I have, a little bit by watching... with my closest friend who's in a relationship for seven years... I guess she's in a much more established relationship - and I kind of saw what they did... a little bit... being an observer in a way. I think when I think about it, it feels I was in the wardrobe, peeping out! (laughter)

LIZZIE: And I wonder Cara, if this anxiety which the uncertainty evokes - could stop you from venturing into relationships?

CARA: I think probably more fear of rejection will do... or I couldn't work out if somebody liked me or not - that's the kind of thing... well, that leaves the only option really: to either ask them. Because I don't really drink a lot, I suppose the other thing of going out with other people and getting drunk, and able to say well, I didn't mean it... or... but I... I would really mean it. (laughter) Yeah, I don't have that excuse - I was drunk or whatever. When I drank a little bit more I met more people. Maybe it was just by being in those venues actually where you were lucky to meet people and again in referring to the PhD, it was enough to cope with, and I really did try. I didn't go out much at all, maybe to a pub with some other people about... but I napped a lot. The napping would be as a result from spending the day with people. I would be like I can't deal with this for longer and I would shut myself in my room and listen to music. I find interacting with people on line or face book when they're not actually in the room, easier and that isn't so tiring. I suppose it's because of the monitoring and the non-verbal stuff really... I don't know...

LIZZIE: It sounds like it's not the lack of being social; it's the lack of know-how...

CARA: A bit of both...

LIZZIE: Both?

CARA: I do know how to be social to some extent and I can do it, and I enjoy it but at the same time it's a strain. In one book on Asperger's I read something of getting a 'social hangover' which is what I think I feel... what I really like of the description is feeling groggy and out of it the next day because you've exerted yourself... socially. I really don't so much feel the need for social interaction as some people, but maybe more than other people do. I don't know... I do desire social interaction but I like periods of solitude as well.

LIZZIE: And I suppose that brings us to the one-to-one relationships when you said it was easier in one-to-one but it was more intimate one-to-one...

CARA: Yes, it's... yeah ... I guess some people get in a relationship where I guess you co-habitat with somebody and I don't think I could actually do that. Or not... unless I have a massive of houses! The financial predicament I will end up in because of.... Well AS and I don't think it likely to afford a massive enough kind of house where one could co- habitat with somebody where we could...

LIZZIE: Avoid bumping into each other!

CARA: Yeah, exactly! While sharing the same house and not seeing each other for several hours! (laughter)

LIZZIE: As a final question I just want to ask - how did you come to get the diagnosis?

CARA: Right. I was seeing the... I was referred to the in-house services of the university during my MA-year and the lady there - and I think in conjunction with the psychiatrist - started to suspect that my thinking patterns were characteristic of Asperger's. I had already had a diagnosis of Dyspraxia when I was younger...

LIZZIE: Okay...

CARA: So we kind of talked about it and my mum suspected it for quite a while - and I could see some characteristics in me but like something I thought I had but wasn't my fault. My mum then, because I mentioned a mental health worker at university, got this book by Rudi Simone called Asperger Girls, which is not like a formal medical book, but it highlighted many Asperger characteristics and she and I thought holy shit, this sounds so familiar!

LIZZIE: Was this...

CARA: I was kind of sitting and thinking: yup..., yup..., yup... - this is beginning to seem like a possibility...

LIZZIE: What when through your mind

CARA: I don't know....

LIZZIE: Relief or a worry?

CARA: Neither at the time. I suppose I just started to think that this might be a thing and that Clare, the health worker and prof. Saunders referred me to Nottingham city Asperger service that would be ... I can't remember when I got the referral but My thinking pattern became of various things I had said and the history of mental health problems I presented with, was beginning to be indicative of Asperger's. So I had developed OCD when I was 13, this eating disorder at the age of about 10, those kind of things which were indicative of Asperger's in girls. My mother had actually suggested this to the psychiatrist I had seen. He was like well, she's got a sense of humour and she has some sense of empathy and stuff. You know, she can't have Asperger's. This would be in 1998. I think I actually do have empathy and what they discovered in Asperger's was that empathy was not indicated in everyday life. I think it has more to do with theory of mind than... well a lack of empathy makes like they are describing you as a psychopath. And it's like no, I can put myself into other people's shoes to some extent or imagine how awful they would feel. So okay, how I got this referral. January 2012. I got some questionnaires to fill in. In February or March I went for the diagnostic procedures and then it was like the end of May, June 2012 I got the 'yay congratulations, you've got Asperger's! letter'. No it was not literally saying that...

LIZZIE: But did it feel like that?

CARA: Sometimes, no, it felt like... at that point I was realizing that the Asperger's did fit me quite well so by that time it wasn't a surprise to me to get that. It was probably not an instant relief but in terms of earlier things, it made things which were kind of related experiences... it felt like it kind of strong... it felt like it linked things together in a more cohesive. I understand why I had repeated periods of health problems because, really, I find it difficult to deal with things.... these reasons... it's a strain... just in everyday living... everything could be a strain ... it's caused a lot of wear and tear on your mind... and also the kind physical thing, the fears of noise I've got, the ... And very bright lights - things I'm kind of sensitive to and that has kind of helped me to alter those things about my life so instead of going down ...I pretty much take myself to the British Library and avoid all the chaos. Like yesterday I actually went out to Tottenham Court Road with all that chaos.

LIZZIE: That's brave...

CARA: Yeah, I met my mum there and also, there are a lot of people there and I find it a bit of ... well difficult to cope with. The noise there doesn't always bother me so much. If I get stressed, the sensory stuff gets worse... and I kind of huddle up and cringe away from it. So yeah, it was a kind of... it was a relief but at the same time the PhD was falling apart and I was hyper stressed and I wasn't kind of ...I think I wish I had also known a little earlier. I can see why it would take such a long time to diagnose. I was probably lucky in meeting the mental health advisors and psychiatrist for creating an awareness of how this presented in girls and it was a bit different. And I mean I suspect maybe there are guys diagnosed who fitted Asperger's because they don't manifest themselves in the typical kind of... in the typically imagined way. (Unclear)...don't have a diagnosis as well but again yes, when I was 16, the psychiatrist suggested Asperger's although my original psychiatrist didn't think so. It was kind of a suggestion floating around in the background but it's something I wouldn't have thought... I knew I was socially a bit awkward, probably like not the best...

LIZZIE: Not the best?

CARA: Not the best socially really... a bit like kind of rather clumsy, not finding it easy and always a bit strange, you might think. Oh, maybe strange is the wrong word... I know I wasn't I don't know ... it's something I wouldn't have thought ... I think I was derogatory towards other people. I think I find it difficult to gel with quite a lot of people - or gel with me or find something different or strange...

LIZZIE: Okay...

CARA: Could I have a drink because I've just talked a lot... do you need to see the diagnostic letter I have?

LIZZIE: No, no that's fine...

CARA: Here is the ... University letter - they did the kind of initial meeting with them - think it's the kind of standard diagnostic procedure.

LIZZIE: Cara, is there anything you would want to add to the interview which you think is very important?

CARA: I don't think so... no I don't think so. If I think of anything, I'll just email you...

LIZZIE: Yes, please do. Really please, please do!